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Rachel Dolhun: 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.

Hi, everyone, and thank you so much for joining us today. I'm Dr. Rachel Dolhun. I'm Senior Vice President of Medical Communications at The Michael J. Fox Foundation. I'm also a movement disorders neurologist and a lifestyle medicine physician. I'm a passionate exerciser, especially a runner, so I'm really excited to be with you here today to talk about exercise. It truly is one of the best tools that we have for our brain health and for managing life with Parkinson's.

We're going to talk not so much about why to exercise, I think we all pretty much know that, but more about how to do it when life, when Parkinson's and everything else seems to get in the way of it. So let's get to what we came here to talk about. We have a great panel of experts, all of whom I've become friends with over the years, so I'm really glad to be having this conversation with them.

First up, we have Lori Quinn, who's a physical therapist and a professor of movement sciences and kinesiology at Teachers College, Columbia University in New York City. Lori leads research on movement, as well as physical therapy and Parkinson's. And she's also a tap dancer, which is one of her favorite exercises. So Lori, thank you so much for being here.

Lori Quinn: Thanks for having me.

Rachel Dolhun: We're also joined by Denise Coley, who's a member of The Michael J. Fox Foundation's patient council and a diversity consultant. She became a Parkinson's advocate with her husband, Bernard, after her diagnosis in 2018. Her favorite exercises include core, the elliptical, and aquatics. And I think, also, anything fun she can do with her grandkids, isn't that right, Denise?

Denise Coley: That's correct. And thank you so very much.

Rachel Dolhun: Thank you for being here. And last, but certainly not least, we've got Larry Gifford. Larry's also a member of our patient council. He's co-founder of the PD Avengers global initiative, and host of the podcast When Life Gives You Parkinson's. Larry was diagnosed with Parkinson's in 2017, and also recently underwent deep brain stimulation surgery for Parkinson's. Larry's favorite exercise is performing improv comedy, and judging by the jokes he regularly shares with us, I'm guessing he's pretty good at it. So Larry, it's always nice to chat with you.

Larry Gifford: It's great to be here, Rachel. Thank you.

Rachel Dolhun: All right, so let's get right in. We've got a lot to cover. And as I said at the beginning, we're not going to spend so much time talking about the why of exercise. We could spend an entire hour just on that. So Lori, could you just briefly tell us about the high points, why should we all be exercising? Why is it so good for us?

Lori Quinn: Yeah. Thanks, Rachel. There are so many reasons why all of us should be exercising, and the evidence, it's quite overwhelming in Parkinson's disease in particular about how it can be neuroprotective. And that means it protects the neurons that are in the brain, and that's an overall concept that we call brain health. So it boosts your brain, your body, as well as your mental health. People sometimes have difficulty with depression or mood changes, and exercise can be really beneficial for that.

It does protect the brain from disease, so one of the things that's being looked at is how much exercise can actually be neuroprotective in preventing people from getting neurodegenerative diseases like Parkinson's disease. This exercise results in changes in the brain in very good ways. And it eases symptoms. So not just being neuroprotective, but when you're doing strengthening exercises or balance exercises, those can help to counteract some of the problems that come with Parkinson's.

Larry Gifford: Can I ask a question here real quick? Is it disease modifying?

Lori Quinn: That's a great question.

Rachel Dolhun: So you mean does it actually slow the disease?

Larry Gifford: Right. Does this change the disease?

Lori Quinn: Yeah, that's a great question. I think the jury is still out on whether it actually changes the disease. There are some studies and some very large-scale randomized controlled trials that are trying to show just that, that they're looking at measures of disease and seeing if doing various types of exercise, and in particular, high-intensity exercise where you're really working out at a very high level, if that has the potential to be disease modifying. So I think we're going to have a clearer picture in a couple of years, but I think the research is certainly moving in that direction.

Rachel Dolhun: And why wait for the research, right? If there's any possibility that it could, there's really no downside, or very little downside to exercise for life and life with Parkinson's. Denise, which one of these benefits gets you going on exercise?

Denise Coley: The one that benefits me most is the last one about the slowing of progression. I'm very goal-oriented. When I was doing a marathon, my goal was to complete the marathon with no injury. My goal now with Parkinson's is to exercise so I can slow the progression and feel better every day and thrive.

Rachel Dolhun: And Larry, last question for you before we move on. You're really vocal about the fact that you and exercise are frenemies. You know you should do it, but easier said than done a lot of times. But for a lot of people, that can lead to things like guilt or, "Why bother with exercise if I can't do it the way I'm supposed to be doing it?" How do you manage that?

Larry Gifford: Well, I try to just keep pushing things up. So sometimes I'll take a class or I'll do improv. And people are like, "Improv, exercise?" But by the end of performing, I'm sweating and high intensity and using my brain a lot. And then also, I've got a great coach in my wife, who will say, "Hey, you want to go for a walk?" And I'll say, "Yeah, I'll go for a walk." So I try to not say no to that as much as I can.

Yesterday, for instance, my son was looking to get energy out and we were locked inside because there was a foot of snow out, so I put him on the indoor bike and then we took turns seeing how far and how fast we could go in five-minute intervals. Even around the house, if you do household activities with intention, you can really work up a sweat and call that exercise.

Rachel Dolhun: Yeah, so bringing it in to your everyday activities, making it fun so it feels less like work or like exercise that we're supposed to be doing, all of these things that we'll talk in more detail about.

But Lori, when we talk about exercise, I know a lot of people have heard, "The best exercise is the one you'll do," or, "Anything's good as long as you're doing it," which is true, but there's more to it than that. So when we talk about what kinds of exercises we should be doing for life and life with Parkinson's, tell us more about that.

Lori Quinn: Yeah. I do think one of the most important things is to understand where people are at and to make incremental changes. But if we're going to just take a broad approach to this and say, "If I was really motivated and I had all the access to equipment and things, what would be the best exercises?" and then we could work down from there.

So the best available evidence right now around exercise in Parkinson's disease, particularly for being neuroprotective and having that potential for being disease modifying, is around aerobic exercise. And this is what's called moderate to high intensity, which we're going to get into, but basically, where you're breaking a sweat. And these could be activities like walking, brisk walking, running, biking, swimming, anything that really gets your heart rate up. And the recommendations is for around 150 minutes a week, at least over three

days. So doing all of that in one day wouldn't be ideal, but breaking it up over at least three days.

But then there's other components that there's equally good research to demonstrate their benefits in Parkinson's, and those are strengthening exercises, flexibility and balance. And you can see some examples here on the slides, but strengthening is where you're moving against your body resistance and things like lifting weights, but also activities like gardening where you're getting up and down and you're doing lots of movement where you're moving against resistance would be considered strengthening.

Flexibility exercises, we often think of things like yoga or Pilates, but there's also just targeting stretching for particularly the trunk muscles, as well as the legs like the hamstrings.

And then, balance. This is a really important component, and there's a lot of good research demonstrating a whole bunch of activities like dance, tai chi and yoga and Pilates can be beneficial to help with balance.

Rachel Dolhun: So there are these four categories of exercise. So I know all of us, Parkinson's or not, we often default to cardio or aerobics, but it's much more than that. So we really need to be thinking about how we're fitting all these four categories into our exercise.

But Larry, I know what you're going to say, so go ahead.

Larry Gifford: So I'm looking at here, three days per week for 150 minutes, and three days a week for 60 minutes and two to three times a week, and then another three days. I mean, God, there's not 12 days in my week.

Lori Quinn: It's a really good point. So there's some people who are like, "I'm all in. I exercise every day." But there's a lot of people who are working full time, have a lot of other responsibilities and don't really feel like they'd have the time to do this.

So I would say a couple of things. One is, if you have to prioritize one thing, at the point right now, I would recommend it would be aerobic exercise. It does depend on where you are with the disease and what symptoms you're managing.

But the other thing is I think that there's some ways that we can try to be creative and try to incorporate all of these. So as you can even see right here, yoga and Pilates are listed both under flexibility and balance. They could also be strengthening. You could do dance exercises, which do get primarily at balance, but they can also be aerobic.

So Rachel, I think on the next slide, we have an example of a calendar that we put together that could show, if someone's working full time and really says, "I do not have time to exercise," this would be just a quick idea of some things that you could do of ways to work it into your daily life. I always say that setting a schedule is one of the most important things you can do for exercise to make exercise a part of your life.

So let's say, on a Sunday night, you sit down and say, "Where is exercise going to fit into my week?" And this is just an example of having at least one day off. I think that's really important. But working in, either before or after work, some things like a morning stretch followed by walking or jogging, which would get at the stretching and the aerobic. Things like a yoga class, if you were interested in that, that could also get at multiple aspects. And then taking the weekends, if that's a time where you have a little bit more time, to bulk up on the activity. So I put in there 9:00 to 11:00 on a Saturday doing something like a walk or a hike, followed by a targeted 30-minute strengthening program. And similarly, on Sundays.

The other thing that I want to mention, and Rachel, you've talked about this a lot, is the idea of exercise snacks, where you might not do it in these longer periods, but you could maybe do 15 or 20 minutes in the morning and then another 15, 20, 30 minutes in the afternoon, and that might work better for your schedule.

Rachel Dolhun: Is that just as beneficial for people? Because we've been getting some questions about that. Are three 10-minute bouts spread throughout the day, can that be just as beneficial as one longer 30-minute session?

Lori Quinn: There is some evidence to suggest that it is, not specifically in Parkinson's, and I think we'd need to do that research to look at these bursts versus these longer periods. But I don't think that there's any reason why it wouldn't be beneficial. As long as you are getting enough repetitions of a specific exercise or getting your heart rate up within those periods, that you can get the benefit. I think it's perfectly fine to spread it out. And certainly, that is better than doing no exercise at all.

Rachel Dolhun: And Denise, tell us a little about your schedule, but also how you came to that. Because I think we can look at this, and if we're not an exerciser, it's like, "How do I go from nothing to, all of a sudden, I'm exercising twice a day some days?" and it can feel really overwhelming. So tell us, like I said, a little bit more about your schedule and how you worked toward that and came to that as the right one for you.

Denise Coley: All right. So I started exercise late in life because I did marathons and three-day walks for five years. With that, I had a schedule just like this. I walked every single day, except for one day on the weekend, and that was a regimen that I kept up so I wouldn't injure myself in those activities. When I was diagnosed

with Parkinson's, I realized at that point I had bone-on-bone in both of my knees, so I had to look at what my schedule was going to be like having bone-on-bone. So I'm looking at physical therapy, how do I get leg exercises, muscle exercises, how to protect the knee but still get the exercise in.

What I finally decided is that I needed to have a mixed schedule. So currently, I go Monday, Wednesday and Friday to the pool for aquatics based on the physical therapy in the water. So I'm getting both the strengthening and the aerobic. Then the rest of the time, I try to on the off days do my elliptical.

But the most important one that I wanted to stress is tai chi. Tai chi is so important, even if you do it once a week, because it teaches you how to keep your balance and to prevent falls. One of my early symptoms was falling. I would fall at work, I would fall at home, I would fall on different vacations. So look to see what is easy.

And if I have a really off day, I have a smovey ring, S-M-O-V-E-Y, and I sit in a chair and I do cardio and weightlifting with that ring, which helps out a lot in terms of I'm losing weight and the doctor wants to make sure that I'm improving my muscle.

Rachel Dolhun: And tell us, also, on your classes, because there's a little more than just the exercise you get from being with a group of people and exercising together, isn't that right?

Denise Coley: That's right. I try to do exercise that I can do with my husband, I can do with the dog or with the grandkids. And usually what happens when the grandkids come over, one person's on the treadmill, one person's on the big elliptical, and I'm on the small elliptical, and then we switch off. For entertainment, one does short bursts, one does long bursts, so I take whoever's available and then they come over to where I am.

But it's really important to have a class if you're into having classes, and there are great classes that I have participated in over time. And then if you have a gym that you go to or a gym in your home, you can switch off. Because I get bored, so I look to see what new opportunity I can try out that will keep me moving.

And also, walking outdoors with our urban poles, both Larry and I have those, and that's a terrific way to get core engaged and to make sure that you're exercising.

Rachel Dolhun: And Larry, tell us about your schedule and how you came to that.

Larry Gifford: Well, my schedule is a little haphazard these days, but it's becoming more important. You mentioned at the top that I had DBS. And so with DBS, because of the dyskinesias, once you get DBS, you don't have the dyskinesias and so

you're not processing your foods as efficiently, and so you can gain weight and so you need to exercise in order to, not just neuroprotect, but to belly protect. So we're mindful of that.

Additionally, my coach, my wife, is great at getting me out and about and really trying to nudge me along. I know there's a balance between, especially with your partners, they don't want to be a nag. But there is a great incentive to walking with your partner. That's one of the things I work on with the occupational therapist is figuring out how I can walk and hold her hand and have a conversation with my wife because I wasn't able to do that for the longest time.

So as Denise said, the classes are great because you have the comradery of the group, and so I also need to get back into that now that I'm healing.

Rachel Dolhun: Yeah, social connection, accountability. If you don't show up for your Wednesday class, you're probably going to get a call from somebody saying, "Larry, where were you?"

Larry Gifford: Right.

Rachel Dolhun: So there's that, too. But I want to say, too, on the gym, for some people, the gym works really well. Other people say, "I don't want to pay or I can't pay a monthly fee," and you don't have to have a big, fancy gym or fancy equipment. There's a lot that you can do just in your own house, stairs, lifting soup cans. You have to be creative and work with an exercise professional to help you get started, but there's a lot that you can do just with your body and with your own space.

Now, Lori, we're getting, understandably, a lot of questions about, "That's nice, you've told me what I should do. But now, how hard do I have to work? You mentioned high intensity. How hard do I have to work? How do I know how hard I'm working? What's too much and not enough?"

Lori Quinn: Yeah. So this is a question that we get a lot. And again, this is really just focusing on this aerobic piece, right? And so the way that we can tell how hard we're working is largely based off of heart rate. If you look at a heart-rate monitor, and many people do have access to a heart-rate monitor like a Fitbit, or if you're at a gym, if you put your hands onto the treadmill or the bike, it will often read your heart rate with relatively good accuracy.

You can determine your heart rate based off a maximum heart rate, but the amounts that you're looking at is getting somewhere between 60 and 85 percent of your maximum heart rate. What does that equate to in terms of how I'm feeling? Let's say I don't have a heart rate monitor on. You can think about it is you can talk, but you couldn't sing. As you get to the vigorous exercise, it's

much more difficult to talk. So if someone asks you a question, you could maybe have one- or two-word answers.

But you can also look at it on a rating scale of 1 to 10, 10 being, "I'm completely exhausted. I can't continue anymore," and 1 is as we're all sitting here right now. And moderate intensity is somewhere between a 3 and a 6 and vigorous is 7 to 10. So there's lots of different ways that you can figure out how hard you're working. Another one is breaking a sweat. Typically, you're getting close to that moderate intensity if you start to break a sweat. So that's another useful indicator.

Rachel Dolhun: And is the target heart rate zone that you mentioned, is that the same for everyone? Is everyone supposed to aim for that 60 to 85% range, or can everybody get there?

Lori Quinn: Yeah. So ideally, everyone should aim, if you're doing aerobic exercise, that you would be getting into that range. That number of what that means in terms of beats per minute is going to be different for everybody based on this calculation. But that's where you'd like to try to get.

But if you can get close to... We've had a few studies where people have gotten into 50, 55%, and they still have demonstrated benefits from that. So I would say getting as close as you can to 60 would be great.

And just a note, once you get above 80, that's more into something like a HIIT workout, which is an interval training, because you really can't maintain. It's very difficult to maintain something like 90% for very long. You tend to do it for very short bursts and then back down.

Rachel Dolhun: And do you have to try different types of exercise to see which are the ones where you can actually get into that target heart rate zone?

Lori Quinn: Yeah, absolutely. So for some people, and there's a study going on right now, the SPARX trial, where people are walking on treadmills and running on treadmills, and that is typically a sure-fire way to get your heart rate up, especially if you walk up on an incline or if you're jogging. But some people, treadmills are difficult for, so we often then recommend other types of machines, so something like a stationary bike or an elliptical, like Denise uses. And what you want to try to do is see if you can increase that resistance to the point where you are getting your heart rate up to that level. So it's not just about how much resistance or how much incline, but it's how your body responds to that.

Rachel Dolhun: And that's an important point, too, at noting that different things will work for different people. So if you have lightheadedness or low blood pressure or you're at risk of falling, maybe the seated bike is better for you. Same with maybe you want to avoid the treadmill.

Lori Quinn: Yeah. And there's a lot of great research on cycling and how good cycling is, so I think cycling, treadmill. Almost we're a little bit agnostic in terms of the device, and we really think the mechanism is around the heart rate.

Rachel Dolhun: So Larry, which tool do you use? How do you gauge how hard you're working?

Larry Gifford: I use my sweat. If I break a sweat, it counts.

Rachel Dolhun: That makes sense. And Denise, how about you?

Denise Coley: I also used sweat. Within 20 minutes, if I'm really working out, I'm in a full waterfall for the rest of the time. And I do want to add a couple things. Make sure you have water with you when you start to exercise. Usually, I like to make sure at the 20-minute mark to get some water. And the next 20 minutes, to do the water.

And my favorite thing is I like to do the elliptical and things inside the house, but I have to have my music. So if I put my music on, I sort of lose track of everything until I look down to see how many minutes and how wet I am from doing the exercises. Those are key factors for me.

Rachel Dolhun: And Denise and Larry, do either of you use a smart watch or any kind of heart-rate monitor or wearable device to help you with exercise?

Denise Coley: Yes, I have an Apple Watch that I use, and I also have a blood-pressure cuff that I'm supposed to use before and after on certain days when they're tracking what my rate has been when I was working out.

Rachel Dolhun: And how did you come to that watch? How does that help you with your exercise?

Denise Coley: Well, it makes me look to make sure that I'm getting into one of those zones of 60 to 74 or 75 to 80, because I'm doing some things by myself, so I'm not trying to talk and sing to somebody. But if I'm outside, I can do it. But the watch is very effective and it gives you a record, so that when you go to the doctor, you can have a conversation about what you're doing with your exercise because that's one of the questions that are asked every time.

Rachel Dolhun: And for some people-

Larry Gifford: And I have an Apple Watch, but it's collecting dust on my desk right now. I just don't like wearing a watch, and so I got to figure out another way. Sometimes it shows up on my phone. If I have my phone in my pocket and I'm doing a lot of walking, it'll tell me how many steps I took, but I'm not sure how that transfers to this because steps are subjective, I suppose, of how if I take 7,000 steps, is that good, is that bad? I don't know.

Denise Coley: And a lot of people have said to do 10,000 steps. Well, I measure my steps, but more important, if I'm on my elliptical and I hold onto the rails, they will measure what your heart rate is so you can tell by just glancing down. But when I'm working out, I don't always wear my glasses, so if I'm going to really be conscious of it, I have to wear my glasses and [inaudible 00:24:37] look down. So you just have to figure out a system that works for you and make sure that you follow through with it.

Rachel Dolhun: And for some people, these are really helpful tools to give feedback and motivation. Larry, you mentioned the 10,000 steps, and not everybody needs to get in 10,000 steps. Especially if you're now not getting in many steps at all, you wouldn't jump to 10,000. But these kinds of games and tools to motivate and give you feedback on how much you're moving.

Larry Gifford: Oh, yeah. You open up the awards or whatever.

Rachel Dolhun: Yeah, you get little trophies.

Larry Gifford: Little trophies, yeah.

Rachel Dolhun: Lori, lots of questions on, "What if we're taking medications?" There's a common medication for blood pressure called a beta blocker that can impact our heart rate and maybe make it harder or impossible to get to that target zone. What do we tell people about that?

Lori Quinn: Yeah, thanks, that's a really important point. So there are some medications, specifically beta blockers, but others, as well, that will lower your maximum heart rate. So you actually could get on the bike and be working out as hard as you can and you're actually not getting above 110, or potentially 120, a relatively low heart rate.

So we have a modified formula for that, which we can share. So there's calculators online that take into account whether or not you're using a beta blocker or a medication that would lower your heart rate.

Rachel Dolhun: And that's something that people don't have to totally navigate on their own. We'll talk a little bit more about your exercise team. But if your head is kind of spinning from all of these numbers, this is something a physical therapist and exercise professional, somebody else can help you with, especially to get started.

Lori Quinn: Yeah, most definitely.

Rachel Dolhun: Larry and Denise, lots of questions and encouragement from folks online about incorporating a mental component into your exercise, so boxing, for example, where you're socializing with other people but you're also doing multiple things at once, you have to get your coordination and your flexibility and your balance.

Do either of you have experience with boxing or something similar, and how do you bring that mental and social and other components into your exercise?

Denise Coley:

So I have done Rock Steady Boxing, and it's really good because it does your body, mind and spirit, so you have to make sure everything's in sync as you're going through. And it really helps in terms of standing up straight, making sure that you are getting the fitness level that you want. And one of the things that has bothered me over time, if I'm tired, you'll see me bend over like this and I don't straighten up until I get some rest because I had not enough sleep the night before.

But when you get into Rock Steady Boxing, you're stretching, you're exercising, and you're working your whole body, so it is really good for you to go and try that out and I would encourage people. And if you're hesitant as a female to do it, what my instructor did, he looked at all the ladies, realized that all of us were, in some different roles, hesitant, and got us bright red gloves. I love my bright red gloves. I thought, "I can do this. I have bright red gloves." So you have to figure out a goal or a purpose, something that excites you about going and doing the exercise, and follow through with that.

And one last thing Rock Steady Boxing and boxing courses, it's a great support group. You're sharing with everybody what's going on in your life, getting examples, working out, but also asking about some things that might be a question that you wanted to ask somewhere else. So it's a great way to exercise and a great way to get fit and a great way to connect because social isolation is not very healthy for Parkinson's patients with isolation.

Larry Gifford:

I was just going to add that I've done the boxing, I've done the system training where you're going around to different stations. And then with the improv, it's really cool because not only are you physically moving in space and time, but you're tracking the conversation, you're having to react in real time, you're using your facial muscles to express yourself, you have to project with a clear voice, you're challenging yourself with all these different things. So you're definitely challenging your brain and you're moving your body and doing whatever you have to do for the scene, so it can be pretty intense.

Rachel Dolhun:

Yeah. And how important and beneficial is that, challenging your mind at the same time as you're challenging your body? Exercise is hard enough as it is, now we have to do math and tell jokes while we're doing it, too? So tell us a little more about that.

Lori Quinn:

Yeah. I'm at risk of saying, "Yeah, this is really important," a lot, but this definitely is something that, I think, a lot of people feel really strongly about and the research is really moving in this direction of not just doing a motor task, so not just moving, but having a movement and a cognitive component to it. So I think that people who are involved in dance and in boxing in Parkinson's disease would all argue, and I completely agree, that you are planning a movement,

you're thinking about things, you're doing coordination and sequencing, as well as moving and getting your heart rate up. So in many ways, those are really multifaceted, great exercises to do.

I think it's a matter of, largely, thinking about those four buckets and making sure that you're incorporating socialization and something that you like to do, as well. I think the motor and cognitive piece that comes into it is really critical as people... I think, as Parkinson's disease starts to progress, the ability to dual task, and for many of us as we get older, the ability to dual task decreases. And a lot of people believe, and there's some evidence behind, dual-task training. Training to actually be able to-

Rachel Dolhun: And tell us what dual task is.

Lori Quinn: Yeah. So dual task means doing two things at once. It's typically a motor task and a cognitive task. So a typical thing is walking and talking, walking while counting backwards. And the ability to do that, we know, decreases as people have Parkinson's disease and as it progresses and as people get older. And we can train that and we can work on that.

Now, we have a limited capacity for dual tasking, so one of the things we often say to people is, "Don't do two things at once. Don't try to cross a busy street while talking on the phone. You're setting yourself up." But in daily life, we can actually try to do a combined exercise where you're planning and thinking and moving and having a cognitive component in addition to the movement piece.

Rachel Dolhun: And are there things that people should be thinking about to be careful getting starting with this, especially if we already have some cognitive changes or we're at risk for falls? How do we get started with this?

Lori Quinn: Yeah, I think the best thing to do is do it in a supervised manner. There's many exercise classes that we haven't even mentioned. There's so many great community-based exercise classes for people with Parkinson's that work this into their programs, as well as things like boxing and dance where the programs are supervised, there's healthcare professionals there, so you're not working on this on your own. I think these are the kinds of things that it's most beneficial when you're working in a supervised manner.

Rachel Dolhun: And Larry and Denise, you both wanted to say something. Denise, go ahead.

Denise Coley: So there are two examples that I have for doing dual tasks. One is tai chi. When you're doing your tai chi movements, you're doing them slowly with breath work, which is so important.

The other thing is people have recommended, if you're walking a lot, to try to incorporate the 4-7-8 breathing as you're walking so that you can be breathing in and breathing out, and also being mindful. So that's doing cognition, as well

as walking. That one, you don't need anything but a pair of shoes. Get outdoors and walk and breath.

Rachel Dolhun: And what's 4-7-8 breathing?

Denise Coley: Four breaths in, hold, six, seven, then go all the way down to eight going out. And I call it the starfish, which is what I use with the kids and I use it with adults in my exercise. So I do it five times.

Rachel Dolhun: And Larry?

Larry Gifford: So mine is not as sophisticated as Denise's, but there are these little toys that are for kids that are called Yellies, and you can get them online for like \$20 bucks. And they only move when you yell at them. And so if you get down on all fours and you have somebody else on all fours and you each have a Yellie, you can race your Yellie while you're exercising and using your voice and counting backwards from a hundred or whatever. And you can really have fun with that and it's really enjoyable.

Rachel Dolhun: So it's a way to work your speech, too. Voice can often change in Parkinson's, get softer. Yeah, so this is a great way to incorporate your speech therapy, as well, while you're exercising. And same with boxing, you're maybe grunting as you're punching the bag. So there's a lot of ways to combine these exercises outside of structured speech therapy or physical and occupational therapy, as well.

So let's move to some tips for getting started or continuing exercise when you have Parkinson's. And these are some general tips, but one of the biggest ones is timing exercise for the right time of day for you. So Larry, let's start with you. Tell us about how you figure out the best time, what you take into account, and then Lori, we'll go to you to add in.

Larry Gifford: Often, it has to do with what I have that day. So I look at my daily schedule and see where I might be able to work it in. Again, I'm not working out every day. I think about it every day-

Rachel Dolhun: That's a cognitive workout, yeah.

Larry Gifford: ... convincing myself to get out the door. But it's really about, "Do I have the time at this point? Can I put it on my calendar and block out that time?" Because I got to take a nap and I got to have a snack. Yeah, so that's really how I go about it.

Rachel Dolhun: And Lori, what other things should people consider when they're thinking about the right time for them?

Lori Quinn: Yeah. And I just want to point out, here we're talking about exercise, but what Larry's referring to is like that. And sometimes, it comes with a bit of dread like, "Oh, I have to do my exercise," and it can be not so much of a positive term. But it's also important just physical activity, which is just moving more throughout the day. And even if it isn't an exercise snack, even if it's just you're not sitting for prolonged periods of time, that you get up and maybe go for a walk even around your house or your apartment or around your block, that you're not having long periods of sedentary time.

But then the exercise is that targeted, planned activity that's trying to address one or more of those four components. And the right time of day is really so dependent on each individual and what works for them. Some people like to exercise in the morning versus at night. But an important thing for people with Parkinson's is the timing of medication. So we typically say that people should be exercising when they're in an optimal medicated state, so usually within an hour of taking your medication, so kind of when you're feeling your best. Some people say that they take medicine to be able to exercise. So you really want to be able to be feeling at your optimal when you exercise because, if you're tired, if you're fatigued or if you're having a lot of symptoms, you're not really going to be able to get the best out of the exercise.

Rachel Dolhun: So yeah, thinking about when your medication is working best, sometimes people will work with their doctor to even take a little bit extra medication right before they exercise, again, dependent on the person, when you have most energy. Again, like you said, some people are morning people. Others, they feel more energy in the afternoon. So really, it doesn't matter. It's really what works best for you.

Lori Quinn: Absolutely.

Rachel Dolhun: We've talked a lot, Denise, about testing and learning. And you've talked about adapting your exercise over time. Tell us a little bit more about that.

Denise Coley: Well, I had a real strict regimen for a long time about walking every day. But what happened with Parkinson's, I had to make a decision. I like the morning time, so my aquatics are at 9:00 in the morning so that I hit the pool and I come energized back home. And then on the days I don't have aquatics, I make sure that I have looked at what time is best. I always think the morning's best, but some days, my 3:00 to 4:00 or 5:00 is the best time, so I'll alternate according to the schedule and how I feel.

The other thing about exercise, besides drinking water, is making sure I get enough sleep and that I have a really good diet because sleep will affect the day and your exercise. So making sure that I get good sleep will really make it a more positive experience, whether it's at the pool or doing elliptical or tai chi or smovey. And I always have a goal every day to try to do at least 20 minutes when I'm not at the pool.

Rachel Dolhun: And that's an important point, it's not exercise in isolation. Good sleep, as much as we can do it, helps our exercise. It also helps us eat better, which in turn helps our exercise. So it all kind of goes together, but that's not to say you've got to figure it all out at once. It's just to say that all of these things go hand in hand and are part of managing life with Parkinson's. Larry?

Larry Gifford: Yeah, I was just going to say, with Parkinson's, there's also pain, oftentimes, people have. And so we should be careful to be mindful of your pain and listen to your body. Because if it hurts to exercise, it's not supposed to hurt. I hear there's some endorphin high or something, but I've never experienced that. But I understand that only work up to the point where you're not going to hurt yourself more.

Rachel Dolhun: Yeah, that's that tune into your experience. Denise, go ahead.

Denise Coley: Some people like to go and do a body scan before they exercise, and that's part of the mindfulness. I tend to do my mindfulness as a separate unit not associated with my exercise. But if you do a body scan and you feel some pain, don't try to increase the pain. Try to go not go that particular hard during your exercise routine so that you don't injure yourself and check out to see whether that's something you need to have some physical therapist or doctor look at.

Rachel Dolhun: Yeah, and some soreness, of course, is right and good after exercise, but it shouldn't be to the level where it keeps you from exercising, you're feeling so fatigued you can't even get out and do the things you want to do day to day. So it's about finding that right level of soreness and good fatigue after exercise, but of course, not pushing to the level of severe, intense, sudden pain. That's stop immediately and talk to somebody, of course.

We have a community member who says, "It's not no pain, no gain. It's no pain, no pain."

Denise Coley: That's true.

Rachel Dolhun: So remember, you don't want that big pain with exercise. That's not what we're looking for. And then, I think, Denise and Larry, both of you have touched on goals. How can goals be helpful in keeping you motivated for exercise?

Denise Coley: If I have a goal, it's my commitment. And I usually write it in my calendar, so that is my headline for the morning or my headline in the evening to see whether or not I made it. Because if I commit to myself I'm going to do something, it's going to be something that I will adhere to in some shape, manner or form. And if I didn't do it, I write down why I didn't do it so that I know, the next day, to make sure to follow up.

Larry Gifford: Good, Denise. Boy, I need to pick up your habits. I think goals are motivating, especially if it involves making commitments to other people or if it involves

just, "Hey, I'm going to get outside today or every day this week once a day, just to do something." For me, just starting at that low level and then working my way up through the week and trying to figure out what's best. But I think having a goal is important because you feel like you've accomplished something once you've done it. I'm a list guy, so you can tick it off the list.

Rachel Dolhun: Yeah, and like you said, it helps you see, if you're working toward that goal, or if you're not, Denise, like you said, I loved that, that you figure out why you didn't work out that day and then address it. But it gives you something tangible to work toward. So it could be a marathon, like you mentioned, Denise. When you've got a race on the calendar, it's happening one way or another. But it can also be a 5K, it can be a run/walk for the Parkinson's community. Larry, you mentioned setting a goal of being able to walk hand in hand with your wife without feeling off balance. So it's important to have goals in exercise. It helps keep you on track and it also helps track your progress toward that goal and adapt as you need to.

Denise Coley: And taking care of animal like a dog, that's another thing that... They'll come and sit and look at you. Sometimes, they'll go and point to the leash. That's a great goal. "He wants to go out for a walk. Let's go for a walk." So it's simple things that are everyday things that are in the home that are available to give you some motivation and a goal.

Rachel Dolhun: And with all of this, that's all fine and good, right? But things get in the way. So what if life or Parkinson's gets in the way? And spoiler alert, if it hasn't already, it will. Denise, as you mentioned, there's those days when you just don't get to it. Or Larry, your schedule just doesn't allow for exercise.

So put on this slide some of the common ones, and we've already kind of talked about pain or injuries, even some on motivation. But Lori, let's start with the fatigue. That's a big one for a lot of people, when we just feel tired as it is, Parkinson's can cause fatigue, medications we take might make us feel more tired. So how do we exercise knowing that exercise will actually help with that fatigue, but it's really hard to get over that initial hurdle of, "I just feel too tired to even get started"?

Lori Quinn: Yeah, and I think this is an important point because people are writing in the chat that they sometimes feel worse after exercising. And what I would suggest is to back off whatever it is that you're doing or start at a very small level. 10 minutes, 15 minutes of whatever activity it is that you're choosing to do. Even if you're in a group exercise class, you could do a little bit and then sit out for a portion of it. And get to a point where you don't feel that fatigue. Because for short bursts, there will definitely be a point where you won't get that fatigue, and then gradually build that up. And I think that's a really important thing is to know your own body and know where that fatigue level starts, and then you could start to build up your endurance.

I also think a really important part of this is working with a healthcare professional. We've sort of alluded to it, but if you were having issues around dyskinesias or falls, which I think we'll talk about, fatigue, pain or injuries, you should consult with a physical therapist or an occupational therapist or a healthcare professional to talk through how you can exercise in the presence of having some of these conditions.

Rachel Dolhun: So let's talk a little bit more about something you mentioned, which is, "What if my symptoms get worse when I exercise?" And I'm going to start with you, Lori, but then I'm going to go to you, Larry, to talk about dyskinesia during exercise. But some people, understandably, their tremor will increase or they'll get more dyskinesia, which is that extra involuntary movement that can come with Parkinson's. And then we wonder, "Is this actually making my Parkinson's worse? Am I causing damage? And also, how can I continue to exercise, despite feeling these symptoms?"

Lori Quinn: Yeah. So I would say that, in general, it's not making the Parkinson's worse. It tends to be a symptom that can happen with some people. Again, I would back off and try to do a little bit less. But I'd also plan it during a time of day where you can have that rest afterwards. And thinking about things like water, that is so frequently an issue where people become dehydrated, that that can exacerbate some of those problems. Making sure that you're eating properly ahead of time. If you're not eating and then you go ahead and exercise, you're more likely to have issues and some of these secondary issues that happen.

So I think really monitoring it, backing off, and thinking about the time of day that you're exercising.

Rachel Dolhun: The time, and then also-

Larry Gifford: Well, and I think we also need to keep track of medicine. I think it's really important because-

Lori Quinn: Yeah, and playing around with the medicine timing. Definitely.

Larry Gifford: Right. Because if you take your medicine and then go work out, you're going to flood your brain with all sorts of chemicals. So maybe take a half pill instead of a full pill right before you exercise because you're going to produce your own dopamine.

Lori Quinn: Yeah. Most people tend to do well somewhere around an hour to two after taking, but it all depends on how often you're taking medication and what your medication dose is, as well.

Larry Gifford: Yeah. Talk to your doctor.

Lori Quinn: Yeah.

Rachel Dolhun: And two things on that, I think, Lori. Is it right that some of this might be kind of a natural response to the exercise?

Lori Quinn: Yeah, for sure.

Rachel Dolhun: So exercise is good stress for us, right? So we're increasing stress, which increases our symptoms.

Lori Quinn: Yeah.

Rachel Dolhun: So some of it might just be, unfortunately, sort of a natural byproduct of the good exercise that we're doing. But then there are ways, too, and I know a lot of our community members talk about, "Well, if I have tremor or if I have dyskinesia, then I adapt my exercise. So maybe I don't do multiple push-ups if that's what I'm doing. I do something that requires more of a longer hold. I don't do sit-ups, but I do what we call a hollow body hold or something like that where I'm holding a move for a little bit longer." So it's kind of about figuring, testing and learning, adapting as we talk about working with a physical therapist or an occupational therapist who can help you with these kinds of things and come up with creative work-arounds.

Lori Quinn: Yeah. And a physical therapist can help people to understand what are the symptoms that are natural and that are to be expected, and those that are not. And certainly, I agree completely on the pain piece. We don't want to be seeing people getting pain. But there's a level of discomfort, I should say, that people will get. So when you get into a higher heart rate zone, if you haven't done that, it's really disconcerting. Your chest is pounding and you could start to get anxious. So again, building that very slowly and working with a therapist so you can recognize, "That's a normal symptom. Being sore, that's a normal symptom." Even some of these increases in Parkinson's symptoms can be normal, but just making sure that they don't get out of hand.

Denise Coley: One of the things that I ran into is I had bone against bone for many, many years, so I had to work with a physical therapist about why I couldn't ride a bicycle. I loved riding a bicycle. Finally, it came up that physical exercise on a bicycle has to be on a recumbent. I cannot any longer do the other bicycle. So it's a matter of addressing what the issue is and finding someone to help you figure out what to do so that you don't constantly have pain or hurt yourself. So the recumbent is my favorite from here on out.

Rachel Dolhun: And that works for you, and for some people, too, there's rowing machines at the gym, more of the upper body. So there's a lot of things that we can look at and work toward to get our exercise in, even despite symptoms.

Lori, we're going to do kind of a rapid-fire because we're getting a lot of questions about different symptoms that can interfere with Parkinson's. So

what about if I feel dizzy or like I'm going to pass out? What should I do with that with exercise?

Lori Quinn: Yeah. First of all, if you feel that as you're exercising, immediately stop. If that's a symptom that you have ongoing, which can be one of the symptoms related to Parkinson's disease, you want to make sure that, when you're exercising, one, that someone is always around and available. So safety first is incredibly important.

But I would then recommend that people work on activities where there's either some level of supervision or you're in a seated position, so things like doing cycling versus walking on a treadmill or running on a treadmill. So just making sure that, if you did get dizzy, that you had a back-up plan that you would be able to just stop pedaling or be able to sit down. Having a chair behind you when you're exercising if you were doing a video, for example.

Rachel Dolhun: And this kind of feeds into our next question, which is on falls. What if I've had falls or I worry about falling, how do I modify exercise? And please do touch on, too, because we're talking a lot about seated aerobics, but what about seated strength exercises, or can you do seated balance exercises? Those kinds of things.

Lori Quinn: Yeah. So, two things. With falls, people have who have experienced falls, and I know, Denise, you mentioned that you had, as well, one of the best exercises to help prevent falls and to help with balance is to actually do things that are challenging and almost bring you to mirror falling or move yourself off balance. You don't want to be doing those things on your own, though. So you want to be doing those, again, under supervision, ideally with a physical therapist, or again, some group exercise programs can really push people to that limit. But if you have falls, that should absolutely be one of the first things that you do.

But if you want to be exercising independently, again, it's similar to the dizziness, making sure that there's support and that you have a back-up. So definitely having a chair behind you if you're exercising, and working on activities where there's just a bit more support so that you're not standing and have the potential to lose your balance.

Denise, I'd love to hear from you on what your strategies were.

Denise Coley: My strategy when I was falling, I didn't know I had Parkinson's, it was really scary because it just happened. Once I found I had Parkinson's, I found the tai chi instructor that I go to, and they spent time showing us how properly to prepare for a fall by having those exercises.

And then Rock Steady Boxing, they did the same thing. They actually had us get down and roll so that we knew how to get up and get down. Those are the things that really helped out a lot. And by the way, Bernard went with me to a

lot of my Rock Steady Boxing and tai chi, and he says, "My goodness, tai chi wore me out." He didn't expect that because it's so subtle because it's so slow moving and you don't really think you're doing anything, just like aquatics, so it was a surprise. But that really helped with the falls.

Rachel Dolhun: And also along the lines of falls, Lori, freezing. When our feet feel temporarily stuck to the ground and we can't move, how do we exercise around that?

Lori Quinn: I think that some of the best exercises for people who have a lot of freezing are to do things that are repetitive in nature. So again, the cycling, but also things like elliptical where, once you get started, you can keep going. So typically, the problem with freezing of gait is on the initiation, the beginning of the movement. So once you can get into a movement where that is very repetitive in nature, the freezing tends to not come in.

But it's also something to try to work on. I know, in boxing classes, it's something that they try to address, as well. And working on that initiation and trying to practice and thing about different cues that can be helpful for you. There's one paper that talks about well over 50 strategies that there are for people who have freezing of gait, of different ways that they can overcome that. So I would encourage people to try to work through some strategies, either on their own by looking it up or going with a physical therapist, to have strategies to try to overcome that, again, so that you can exercise.

Rachel Dolhun: And for some people, music can be really helpful, too. Not just a motivator in and of itself, but for helping keep that rhythm with freezing, too. Yeah.

Lori Quinn: Sorry. The dance repeating people would say that's another reason to do dance. Yeah, because it really does help with initiation of movement.

Rachel Dolhun: Larry, question for you in cold Vancouver. What about exercising outside in the colder months, how do we manage that?

Larry Gifford: Oh, no. I exercise indoors. I've got a Theracycle and I've got my music. I mean, you can walk outside if it's not snowing, but you don't have to do it outside.

Now, Tim Haig, who's in Winnipeg, will bicycle when it's 30 below. That's just not what I like to do. So I think it's up to the individual, but for me, I'm trying to keep it indoors.

Rachel Dolhun: Yeah, having a back-up plan, moving indoors if that's possible for you. There's also a saying, "There's no bad weather, there's just bad clothing." So it really is about figuring out how to layer and dress, having wind-resistant or waterproof resistant clothing.

Lori, maybe you can just briefly, briefly touch on what else we should be thinking about with weather and exercising outside with Parkinson's, if the sidewalks are icy or those sorts of things.

Lori Quinn: Yeah. I mean, I would really encourage people to not let weather, when they can, impede their ability to get outside and walk, but I understand that, for some people, it's just not as enjoyable. But if you can try to push yourself, I think something that was already mentioned was the urban poles where you can have some ability to increase your base of support and provide a little bit more stability when you're walking outside on icy or uneven surfaces. So I think that's a really important piece of it.

But there's so many... I mean, one thing we definitely learned from the pandemic was there's so many different ways that people can exercise at home. There's a lot of exercise videos online. Again, I would be a little bit cautious with just jumping into something, but maybe, again, working with somebody to take a look and see what the best exercises for you to do are. But there's lots of different options for exercising at home, but I would also recommend trying to get out there. It's very cold in most parts of the US right now.

Rachel Dolhun: And motivation, on this slide and throughout our conversation, we've talked a little bit about motivating ourselves. But as we move to the next slide, how do we motivate our loved ones? This is a really tricky balance for a lot of people where they say, "I want to encourage, but I don't want to feel like a nag." And we actually had a question from somebody in our audience saying, "How can I motivate my husband to do this? He says he doesn't want to or he can't do anything when I try to suggest things."

So Larry and Denise, I'll start with you. What helps you as a person living with Parkinson's? What's most beneficial when somebody approaches you to encourage you for exercising?

Larry Gifford: Well, what's really helpful for me, and my wife will say, "Don't exercise for yourself, exercise for your family," because I'm trying to stay healthy for them and so I can participate in life with them. And the bottom line is with anything, you're only going to do it if you want to do it. If you want to quit smoking, great. But if people are telling you to quit smoking, you're not going to quit smoking suddenly. Nobody's convincing anybody to do anything different on Twitter. You have to want to do something, so you have to make that commitment to yourself.

Denise Coley: So I agree, having the commitment to yourself. But I also have to say that Bernard has been really great about reminding me about exercise and about sleeping and eating and actually working out. And this picture actually was taken on one of our trips, and we had the poles and we were hiking all around Alaska, which was something fun to do together. And then my brother joined us one of the trips, and that really was a great motivation piece.

And shared activity goals are really important for both people. He gets a benefit, I get a benefit, and we're doing something together, which is so important. Keeping that connection, not being isolated, and finding out different ways and things that are of interest to both of us.

Rachel Dolhun: Lori, anything to add there?

Lori Quinn: No, I think these are all great suggestions.

Rachel Dolhun: Yeah, it can be really tough. I think the last one, too, is be a good role model. If you're out there doing your exercise by yourself, I think other people seeing that, you inspire other people when you're out saying, "I'm going to go for a walk with or without you." And I think sometimes that gets people, like I said, inspired and motivated, as well.

I can't believe we're almost at the end of the hour. We are at the end of the hour. And I know we just flew through so much information and it can feel overwhelming if you're new to exercise or even if maybe your motivation has waned a little bit. But it's really about just taking a step. You don't have to figure it out all at once, you don't have to have that calendar we threw up that has you exercising twice a day. It's really about just getting started, and it's never too little, it's never too late.

Unfortunately, we're out of time, so I want to thank Lori, Denise and Larry so much for your contributions to that guide and also for your contributions to this conversation. It was fun and it was information filled, so thank you so much for being here.

Lori Quinn: Thank you.

Denise Coley: Thank you.

Rachel Dolhun: Well, that's it. Like I said, I hope that this inspires you and your loved ones to continue or to start exercising. It really is one of the best things we can do for ourselves and for our loved ones. Thank you for joining us. Again, thanks to our panelists. And thank you and have a great rest of your day.

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