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MJFF: 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.

Dr. Rachel Dolhun: Hi everyone and thank you for joining us. I'm Dr. Rachel Dolhun, a movement disorder specialist, Senior Vice President of Medical Communications at The Michael J. Fox Foundation and your moderator for today's webinar. Today, we'll be discussing thinking and memory changes that can happen in Parkinson's disease. This is a really tricky and tough topic for a lot of people. So we hope to open a discussion, help you ask questions and talk to your loved ones and doctors, and learn more about this topic. We'll cover ways to manage these changes, tips to boost brain health and the latest research toward new treatments.

Dr. Rachel Dolhun: This webinar is brought to you with support from Acadia Pharmaceuticals, and while their support does help make this educational program possible, it does not influence the content, perspective or panelists selection. If you have a question during the webinar, you can type it into the Q&A box near the middle of your screen. We'll get to as many as we can throughout the hour. And if you want other helpful information, you can check the resource list on your screen. We've got a lot to discuss today, so let's get started. Let me introduce our panelists.

Dr. Rachel Dolhun: Dr. Lenora Higginbotham is an assistant professor in the Department of Neurology at Emory University in Atlanta, Georgia. She's also a 2018 graduate of the Foundation's Edmond J. Safra Fellowship Program, which is building a network of movement disorder clinician researchers around the world. Dr. Higginbotham also helped care for her grandmother who lived with Parkinson's and thinking and memory changes. Welcome, Lenora.

Dr. Lenora Higginbotham: Thank you, Rachel. Nice to be here.

Dr. Rachel Dolhun: We're glad to have you. Dr. Melissa Armstrong is an associate professor of neurology and Director of the Dorothy Mangurian Clinical-Research Headquarters for Lewy Body Dementia at the University of Florida. Her research focuses on the lived experience of people with Parkinson's disease and Lewy Body Dementia. Thanks for being here, Melissa.

Dr. Melissa Armstrong: Thank you.

Dr. Rachel Dolhun: And last, but certainly not least is Steven Brody who recently retired from practicing corporate law for over 30 years. Steven was also diagnosed with Lewy

Body Dementia about three years ago. He lives in Larchmont, New York. We're so glad you're here, Steven.

Steve Brody: Thanks for having me.

Dr. Rachel Dolhun: So let's jump right in. As I said, we've got a lot to discuss, so we want to get started. And first we sort of want to set a baseline, set the stage for what we're talking about today. We often talk about cognition about thinking and memory, but what does that actually mean? So Dr. Armstrong, I'll start with you and we see on this slide, many different words, and these are different parts of cognition. So could you just give us some basics about what cognition is and what it includes?

Dr. Melissa Armstrong: Sure. When I think about cognition, I often use the term memory and thinking. So often when we think about change, as we think about memory, can we remember something that was told to us? But cognition is really a lot more than just memory. And sometimes it's those other factors that are more of an issue in Parkinson's disease. So Parkinson's disease can affect how well we can pay attention to something and focus on something. Parkinson's disease can affect how we can multitask and handle complex ideas or more than one idea at a time. It can affect visual spatial reasoning so where things are in space. This is a particular issue when people are driving. There can be language involvement, like the tip of the tongue syndrome, where you know what you want to say, but you can't get it out. And so when we think about cognition, memory is one part of that, but there are also other parts of that.

Dr. Rachel Dolhun: That's really smart. And we actually had a question beforehand of, is it common to not be able to verbalize a comment or a question, to know what you want to say, but not be able to say it. And you sort of answered this already.

Dr. Melissa Armstrong: Absolutely. That tip of the tongue syndrome where it's right there is a really common thing we see in Parkinson's disease.

Dr. Rachel Dolhun: And one more question before we leave this slide, because in Parkinson's we often talk about executive dysfunction. So can we just spend one more minute on describing exactly what that means?

Dr. Melissa Armstrong: Yeah. So executive dysfunction covers a number of different things, but it's kind of those higher level types of reasoning. So multi-step activities where you've got to do a bunch of different things in order. I mentioned multi-tasking. Multi-tasking is one of those things that can be a challenge even in earlier in Parkinson's disease. So some of that complex reasoning, making complicated decisions, following complicated commands, those things are all part of executive function.

Dr. Rachel Dolhun: And I want to move into the next slide now and move to you, Dr. Higginbotham where we've talked now about what cognition and what memory and thinking can entail or include. But it can change as we get older, but also with some diseases like Parkinson's and other conditions. So take us through that a little bit. What's normal? That's a common question. And what sometimes is something else as we get older?

Dr. Lenora Higginbotham: So as we age a bit, it is common to have a certain level of just senile aging and a bit of impairment in terms of memory, but definitely when it starts becoming noticeable in certain aspects of your life or daily functioning, this is really definitely abnormal. And so sometimes it is a little bit difficult as we age, because a lot of times we're very used to a certain level of functioning, high powered jobs, this and that. So it is sometimes very difficult to know if certain mild changes may represent something that you need to worry about. Say it's not influencing your daily life and we call this mild cognitive impairment, but sometimes it's a little bit difficult to know, is it really like something that's clinically something substantial. Or if it's something that we don't need to worry about as much.

Dr. Lenora Higginbotham: And that is the kind of gray area where I would really encourage you to talk to your neurologist because there are actually different tests that we can do. Screening tests in the clinic, but we can also do more involved testing with our neuro psych department to really kind of help tease out, especially with that detailed neuro psych testing. They take into account your education, where you were at your initial peak functioning, where you should be now, et cetera, et cetera. And they have these ranges, make them let you know, what's normal, what's more mild cognitive impairment being that there is a significant decline, but it's not affecting your daily functioning. And that what may be broaching on dementia, where it is definitely affecting your daily functioning. And you usually have those domains that we talked about, usually impairment in more than one of those.

Dr. Lenora Higginbotham: And so, I think Rachel, it's so hard. It's just like because I know patients come and they're just worried about this thing. I walked into a room and I forgot what I was looking more, this sort of thing. But if you're noticing changes, just anything you're worried about, just talk with your neurologist because there are different ways that we can help you ...

Dr. Rachel Dolhun: That's a great point to ... We can't help unless we know that this is a concern, but it can be hard to talk about. And Melissa, I don't know if you have any other tips because this is such a common question. Is it age or is it something else? And I often tell people, ask other people your age with and without Parkinson's or with or without other conditions, if they're experiencing the same thing you are. So you can sort of get a baseline for comparison, but are there other things you can do to figure out if it's age or something else?

Dr. Melissa Armstrong: Well I do agree with what was mentioned, talking about it, both with other people, with your doctors can be helpful. There can be cognitive tests we can do in the clinic. Little ones, as well as the neuropsychological testing that was mentioned. I do think some of those things you hear about, oh, I forget why I went into the other room. Those are really common and so smaller things like that, I don't worry as much about. But if there's a change, if you used to be able to do the taxes and you can't, or you used to pay all the bills and now you're forgetting them. If other people in your life are mentioning that they're concerned, those are some things that raise red flags for me.

Dr. Rachel Dolhun: That's a really good point. And I'll stick with you before moving to Steven to hear more about his experience. But as we're talking about these changes that can happen with age, but also in Parkinson's. I want to talk about the changes that can happen in Parkinson's and be very clear, these don't happen in everyone. And if they do happen, there's a range of changes that can occur. So can you talk about that a little bit to our audience?

Dr. Melissa Armstrong: Sure. So with Parkinson's disease, it's gradual and things change over time. So we do have these labels, we give different parts of cognitive impairment, but it's not as simple as saying you're in a normal box or you're in a mild cognitive impairment box or you're in a dementia box. It really is a spectrum, but we use labels to try to make it, to try to identify when something is happening, but it's not like there's a day where you've switched over. It really is a range of experiences for people with Parkinson's disease. There can be early changes like multitasking becoming more difficult, or you're still kind of in that normal range, even though we know that Parkinson's is making things more difficult. Mild cognitive impairment is when there is a clear change from before and we can detect that on testing, but it's not yet to the point where it's really having a big impact on some of our key day to day function.

Dr. Melissa Armstrong: It might make work a little bit harder or something at home a little bit harder, but you're still functioning pretty normally, even though your memory and thinking are not the same as it used to be. So that's that mild cognitive impairment stage. And then we use the term dementia when the memory and thinking problems have gotten bad enough that they are really affecting day to day life, but that's all a spectrum. And so sometimes people say, well, am I in mild cognitive impairment or dementia? Well, and that's a spectrum too. So I do think we should look at the memory and thinking changes, not as a box, a box, a box, but as something that we can have some gradual changes over time. And just like there are gradual physical changes, there can be gradual of memory and thinking.

Dr. Rachel Dolhun: And a real common question when we talk about dementia, this more significant change in thinking and memory that impacts our daily life. Tell us a little bit more. I think a lot of us default to thinking Alzheimer's is equivalent to dementia and there are other types of dementia. So tell us a little bit more about that and also tell us about Lewy body dementia.

Dr. Melissa Armstrong: Yeah. So these terms are really confusing. And so if you are on this call and you are confused, you are not the only one. Even in medicine, these terms can be confusing. And one of the reasons it's confusing is because there are a lot of what we call umbrella terms. So it's a general description and then there are a bunch of things under it. So dementia is really a umbrella term and it says the memory and thinking has changed from what it was before. And that change is enough to have a pretty prominent effect on day to day life. And in the United States, Alzheimer's disease is the most common dementia, but it's only one of them. You can also have memory and thinking changes related to stroke, for example. And then one of the other dementias is Lewy body dementia, but Lewy body dementia itself is an umbrella term.

Dr. Melissa Armstrong: And so Lewy body dementia includes two diseases. It includes people with Parkinson's disease where the Parkinson's disease has progressed and really affects memory and thinking as a very prominent part of the Parkinson's disease. And it also includes a disease called dementia with Lewy Bodies. And dementia with Lewy Bodies is diagnosed when the memory and thinking problem is prominent right upfront at the very beginning, along with some of those Parkinson physical symptoms.

Dr. Melissa Armstrong: Now Parkinson's disease, Parkinson's disease dementia and dementia with Lewy Bodies are like this. Some specialists even say that they're just two sides of the same coin, but you can have a little bit of a different experience if your Parkinson's disease starts with the real physical symptoms versus if the problem starts with the real memory and thinking symptoms. And so I do keep those things diverse, but I do want to point out that sometimes people see me and they say, oh, I was diagnosed with Parkinson's disease, but I learned now that was wrong. What I have is Lewy body dementia. And that is a little bit of a misconception. If you have Parkinson's disease and it starts to affect your memory and thinking, that can be Parkinson's disease dementia, which is one of the types of Lewy body dementia. But the vocabulary, it's rough. Even for medical professionals, it's rough. And so there is actually a committee at the NIH right now saying, should we change what kind of vocabulary we use with dementia?

Dr. Rachel Dolhun: Yeah. I like what you said. If you're confused, you're in the right spot. So we often have to talk about this multiple times, try to explain it different ways because the vocabulary is very confusing. But Steven, I want to bring you in now because you were diagnosed with Lewy body dementia about three years ago. So we'd like to hear a little bit more about your symptoms, what you experienced and how you came to be diagnosed.

Steve Brody: Yeah. Happy to do that. I'm on the patient side of the discussion. So I bring something meaningfully different, I think. And I can attest to some of the symptoms that I've seen and you mentioned them on the LBD side of this. And I'm looking at issues and deterioration that happens over time. It's not happening that quickly for me, which is the good news. And I do think that there are ways to slow down the progress. Some people probably have different views about that, but the thing that I wanted to touch upon, because I thought it played into what a few of you said, is that diagnosis of Lewy body disease is a very difficult thing for the doctors to do, as you all probably know, and it means that sometimes it's very slow-moving diagnostic situation that we have. So for me, a few years went by where I thought I just don't feel right. And my doctors, all of whom are wonderful people, said, "Ah, forget about it. It's pseudo-dementia," or, "It's something we could deal with through talking therapy or magnets," and people like magnets. And these are the kinds of slow to diagnose issues that we have. The way I figured it all out was I went to see a neurologist, one of several, and he said to me, "Walk down the hallway and come on back." So I walked down the hallway, I came on back and he said, "You've Lewy body disease." So he's a very smart doctor. But that's where I am today. I'm developing, but I would be characterized as mild. And we patients really love to hear that phrase mild.

Dr. Rachel Dolhun: Well, I think two important things, what you said. One is that it can be mild. So like Dr. Armstrong was talking about, there's this range of changes. Even when you have dementia, there's a range from mild to more moderate, so everybody's very unique in this regard. But when you're talking about the difficulty with diagnosis, that's a very common one. And Dr. Higginbotham, can you tell us how this is diagnosed and why it is so difficult to get a diagnosis even quickly?

Dr. Lenora Higginbotham: Yeah, I think that... So let's just divide a little bit, the two different types of Lewy body dementia. So dementia with Lewy bodies will come in with significant cognitive changes off the bat, and that will be one of the primary complaints that an individual has off the bat. And all of the dementia diagnoses are done basically on clinical testing.

Dr. Rachel Dolhun: We don't have a blood test. We don't have a brain scan test.

Dr. Lenora Higginbotham: We don't have anything. But right off the bat, the neurologist is clued into, "I need to be focused on cognition here because this is a problem." Usually dementia with Lewy bodies, they'll have hallucinations to psychosis, all these problematic what we call neuropsychiatric complaints that kind of combine psychiatry and cognition. And so, the neurologist was already clued in that this is likely some sort of prominent cognitive syndrome. And I'm not exactly sure, Steven, on your progression, but I think the diagnosis for dementia with Lewy bodies is hindered a little bit by just the fact that there's Alzheimer's out there and other things that it can mimic. But one of the biggest misdiagnosis of dementia with Lewy bodies is Alzheimer's disease because that's automatically what people think about cognition and the onset of cognition. So I think that has, the problem with dementia with Lewy bodies is more of a misdiagnosis. But definitely at least a neurologist is clued in already to be thinking about cognitive and dementia syndromes.

Dr. Lenora Higginbotham: I think for people who start off with Parkinson's disease, and then that diagnosis of Parkinson's disease dementia can be a lot slower, right? Because we have these long relationships with our patients, and I know very reassuring in clinic all the time. And we're trying to basically reassure you that it's slow. The progression's slow. Things happen just in very minimal increments. But that can make it a little bit difficult to really get at that conversation that, look, this looks like dementia is forming here. Just because those cognitive changes can come out, whether the patient discusses them every time, but they come out very slowly and sometimes the diagnosis is just really hard for the patient and the physician to get there over time because it's so gradual.

Dr. Rachel Dolhun: So it speaks to the importance of making sure that you're in regular communication with your doctor or you're bringing up these concerns, your care partner is bringing up concerns if they're seeing anything different.

Larry Gifford: A landmark study that could change the way Parkinson's disease is diagnosed, managed and treated is recruiting participants now. PPMI, or the Parkinson's Progression Markers Initiative, needs people with add without Parkinson's, especially people aged 16 up who have close relatives living with the disease. Take a short survey today at michaeljfox.org/ppmi to see if you're eligible. That's michaeljfox.org/ppmi.

Dr. Rachel Dolhun: I want to move on to talking about some of the symptoms. And Steven, I'd like to come back to you here. So we've talked about how cognitive changes can have an effect on your life. And some of these things are real big things, your work, your driving, your relationships with other people. So Steven, tell us your experience here a little bit more about your symptoms and how they changed your daily life.

Steve Brody: Yeah. For me, the things that are most troubling are some daily life changes. So challenges with creating a schedule. That can be very hard for me and disruptive. Other people are moving along and I'm kind of hanging back and not moving as quickly as others would be or as I should be. Also, I have some issues with working on projects. So for example, I'm working with some of the folks on a book, which is great to be working on the book, but it creates other challenges. And then, maybe most pronounced, at least this morning, was a medicine regimens, which I was struggling with a bit this morning. And again, I think that's not unusual, but it can take up a bunch of your day trying to figure out what those issues are and how to deal with them. And the most valuable way for me to do it is to, as a patient, I look to my caregiver as a source of coordinating all these issues. And that, to me, is one of the greatest resources, if you have somebody who's out there who's figuring out things for you, it makes a huge difference.

Dr. Rachel Dolhun: Yeah. So important to have support if you have a good care partner or a spouse who can help, but building your support network, which we'll talk about a little bit more. And Dr. Armstrong. I want to come back to you on, on some of the other things on this slide, because these are real big parts of our lives, and driving is a good example of this, even working. How do you know, how do you think about this? If you have early changes, mild changes, how do you think about these things? When to continue working, stop working, continue driving, stop driving?

Dr. Melissa Armstrong: Now, these are tough, tough decisions, tough assessments to make. And like so much of Parkinson disease, there's a lot of variability from person to person, and a lot that each person needs to work out with their family, their employer, and their physician because when the right time is to step back from work might depend on your age, the type of job that you do and the kinds of demands that the job has. And then, also the kinds of challenges you're facing. And then, there are those personal issues, big life issues about, I have kids in college I'm trying to pay and my retirement age. And so, it's hard to have blanket guidance for when is the right time to back from work or to step back from driving.

Dr. Melissa Armstrong: But some of the things I talk about with the people that I partner with in clinic is, are you able to do your job adequately? Maybe you're not the same that you were before, but we all change. Can you do the parts of the job that you need to do at the level you need to do the at, even if it's not quite as great as you were before? Are there modifications that we can make, either physical modifications or ones to help with cognitive, that would let you continue to be successful at work? And those modifications would be different from job to job, but can you be allowed to have more time? If you're a slow typist, but you can still have clear speech, can you dictate? And so, for each person we think through how is the memory and thinking, or the Parkinson's more generally, affecting success in the workplace.

Dr. Melissa Armstrong: For driving, that's a challenge too, because you're thinking of memory thinking, cognitive changes, but you're also thinking of physical changes. And that's a place where we really want to be cautious because no one wants to hurt themselves or someone else. And there are several parts of cognition and Parkinson's that can affect the ability to drive safely. And the top two are that visual, spatial reasoning. How close are you to a car? How close are you to a curb? But also that executive function you asked about, the multitasking. Driving is all about multitasking. And you can imagine if you have trouble multitasking and trouble seeing exactly where things are in space, that has a lot of implications for driving safely.

Dr. Rachel Dolhun: And there's a lot that we can do to address this, right? You can talk with your doctor, talk with your loved ones, you can get a driving test. So the important thing is to talk about it and describe it so that we can keep you on the road safely, if that's possible, or look for other modes of transportation.

Dr. Melissa Armstrong: That's absolutely right. Driving is a big part of our independence. I don't think any doctor wants to recommend that someone doesn't drive. I really like driving assessments because they are very objective. Do you have the skills you need? And in the clinic, the first assessment, and then do you have the skills you need on the road? And there's nothing in it for them. So I've had all the responses. Yes, this person can drive safely. This person is still driving safely, but they're not doing it as efficiently as they used to be. We should keep an eye on this. And I've had them say this person just isn't safe on the road anymore. So that objective assessment can be really helpful for the person with Parkinson's, for the caregivers and for the physician. So we say let's take our opinions and our emotions out of it. Let's look at the facts.

Dr. Rachel Dolhun: That's a great point. And Dr. Higginbotham, we're getting a question. We've been talking a lot about thinking and parts of thinking and memory and how those can change, but can other things happen when you have cognitive changes? Can you have mood changes or can you have hallucinations, see things that aren't there, those sorts of things? What can go along with cognitive changes in some people?

Dr. Lenora Higginbotham: Oh yeah. So a number of things can happen. And I don't think we've addressed this quite yet, but the reason why that we think that changes in Parkinson's disease kind of progressed from mild cognitive impairment to more dementia is that there's this spread of these proteins called Lewy bodies throughout the brain. But one thing I really want to emphasize is that the pathology starts in the basal ganglia. And we usually think about this part of the brain as being mostly motor and function. But that particular area of the basal ganglia sends out tracks to a bunch of different places, right? And so, one of those is the final cortex, which gives you executive dysfunction. Another one is limbic areas, which can give you emotional problems, so depression, anxiety. These are so common in Parkinson's disease patients. Over half of patients can have depression, anxiety, even outside of any significant cognitive changes.

Dr. Lenora Higginbotham: These are all when the Lewy bodies are in the basal ganglia. They haven't even spread yet to where they're giving you dementia. These are just from those initial Lewy body deposition or accumulation in the basal ganglia. So depression, anxiety, that executive dysfunction that we keep talking about. One thing I want to emphasize is that that is not necessarily a prelude to dementia. Okay? That happens from Lewy bodies just being in your basal ganglia. The dementia comes when they start spreading to the cortex. Okay? So that executive dysfunction, I tell patients, "Don't worry. This can often be problematic throughout Parkinson's disease. It doesn't mean you're going to get dementia in a few years. This is just something that can happen at the start and just linger and not even change a whole lot, just linger because those basal ganglia connections are messed up."

Dr. Lenora Higginbotham: But then, once over time, and we're usually talking decade plus in Parkinson's disease, these Lewy bodies can get to the cortex. And when they get to the cortex, there's a whole other host of different things that can be involved. One is your occipital cortex, which controls visual function. And so, yes, visual hallucinations can be a huge part of this, particularly Parkinson's disease dementia, but also Lewy body dementia. And then, other aspects of cortical and limbic function, where these Lewy bodies spreading, also do other aspects of psychosis or psychiatric function. So basically one other big thing that runs along with the visual hallucinations or delusions. These can be another aspect of psychosis that people have, where you have this kind of fixed belief that's not really rooted in the truth, and it's very hard to redirect that fixed belief. Some of these can be debilitating.

Dr. Rachel Dolhun: Yeah, that's really a great, but a very detailed description. So just to kind of break that down, you're talking about some of these proteins that can change in the brains of people with Parkinson's, and they can also change in ways that can impact cognitive, cognition and thinking and memory. And some people who have thinking changes can have mood changes as well, whether those be depression or anxiety or apathy, not being motivated, or sometimes even a little bit of a change in personality or behavior. And then, you also mentioned these other changes, again not in everyone. But sometimes, especially if the changes are more significant, some people can have hallucinations, seeing things that aren't there, delusions, believing things that aren't true. And again, everyone is very unique and has their own course with these symptoms. And there's a lot that you can do about them. Now, I want to pause here for just a second and let you know about an opportunity for everyone on this call, whether you live with Parkinson's or love someone who has Parkinson's or thinking and memory changes. And like I said, we're going to move in a second to talking more about ways to support yourself and your loved one. But I want to pause here to mention the Parkinson's Progression Markers Initiative. So PPMI is The Michael J. Fox Foundation landmark study that's looking for ways to diagnose and monitor Parkinson's and eventually ultimately hopefully prevent it. And the study is now recruiting people, parents, brothers, sisters, children of people with Parkinson's. You can take a short survey to see if you're eligible at the link on your screen there, michaeljfox.org/ppmisurvey.

Dr. Rachel Dolhun: And that's also in the resource list. The study is also looking for people who've been recently diagnosed with Parkinson's within the past two years. And you can learn more on our website about that as well. So once we finish the webinar, go jump right in and learn more about that study. So moving back onto our topic, I want to focus on what we can do about cognitive changes. And Dr. Armstrong, I'll start with you, whether you worry about these changes, Parkinson's or not, just the fact that we're all getting older and these could potentially happen, or whether you have them. There are a lot of steps that you can take. And one of the most common questions we get is, "What's the diet that I should take for brain health? Or what exercise is the best one to do?" So talk to us a little bit about those.

Dr. Melissa Armstrong: Sure. So I think when people ask me about brain health, one of the most important things you can be doing is exercise. There really is research across brain conditions now, including in Parkinson's disease specifically, that physical exercise is good for brain health. There's a lot of different research about people with Parkinson's who exercise, they do better physically. But there's a lot of interest now also in how exercise can affect our memory and thinking whether that's in Parkinson's disease or aging or Alzheimer's disease. There's really growing research that physical exercise is good for brain health. And so I think one of the most important things that all of us can be doing is exercise. Now in Parkinson's, different kinds of exercise probably help you in different ways, both physically and mentally. And I'm not sure that there's a one best exercise, but one of the things that I emphasize to the people who I partner with is one, probably one of the best exercises is the exercise you will do.

Dr. Melissa Armstrong: And though I do want people to figure out what can they do and commit to. And then two, it's really important that the exercise you do is safe. So as specially as the Parkinson's advances, I like things like seated bikes rather than the recumbent, or it's so low on the ground that it's hard for you to get up, or the upright where you have to swing your leg over and have balance. Maybe a seated bike, a chair height bike is the way to go from a safety perspective. So the exercise you can do and the exercise you can do safely is a good place to start. From a diet perspective, I think there's increasing research supporting something called the Mediterranean diet. And that's something that the dieticians at our center counsel people on. But all of these things are also still a work in progress.

Dr. Rachel Dolhun: Eat well, exercise, those are going to be good for you no matter what, right? Lenora, we get a lot of questions about brain games. So is there one that's better for brain health than another? Do these actually work? Tell us a little bit about those.

Dr. Lenora Higginbotham: Yeah. A bit of a controversial question. I mean, I think from most of the research that we've gotten on playing the same brain game over and over really does not necessarily improve your mental flexibility, your ability to operate in everyday life. You get really good at the same game, but you may not pick up the function that you would like to in everyday life. So what I usually tell patients is definitely you can play games or do word searches or crosswords or whatever that kind of exercise your mind regularly, that's so good. But make sure to mix it up. Don't let that be the only way that you're trying to improve your mental flexibility. You need a variety of things that exercise your mind. So I would just do a variety of different kinds of games. But definitely anything you can do, crossword, anything is usually helpful.

Dr. Rachel Dolhun: And Dr. Armstrong, a question for you. What about these over-the-counter vitamins and brain boosters we see advertised on television that help with memory and thinking? Is there anything we can take like that, that will help?

Dr. Melissa Armstrong: So from my perspective, most of those things that you'll see on TV just do not have the compelling research behind them. We want to find those supplements that will do something, but despite what they advertise, there really is no good vitamin or supplement shown to routinely help brain health. Some of those supplements do have a nugget of truth behind them. For example, we know that if you're low in vitamin B12, that can affect your memory and thinking. And if your doctor finds that you're low in vitamin B12, you absolutely need that replaced, usually by a shot rather than a pill. But there's not a lot of good evidence that just taking a general B vitamin is going to do much for your memory and thinking. And we do know too, that some of these herbs and supplements, they can interact with medications. It's not that they're not medication, they're another pill that has interactions and side effects.

Dr. Melissa Armstrong: So in general, my approach is to say there's really not a lot of research to support those supplements yet. But there are over-the-counter medicines that can do harm, and I think the most common one is the over-the-counter sleep aids. Not melatonin, there's good research to support use of melatonin for sleep and Parkinson's, but things like diphenhydramine that's in Benadryl, Tylenol PM, Advil PM, ZzzQuil, a lot of these different over-the-counter sleep supplements. If it says diphenhydramine on the label, that can make people with Parkinson's and older adults in general really confused. And so you have to be careful about over-the-counter supplements and over-the-counter medications.

Dr. Rachel Dolhun: And make sure that you talk about this with your doctor. So one of the first things we do if you come and say, "I'm not my... I'm cloudy. I'm just not thinking like I used to," look at your other medications, prescription and not, so that we can see if any of those is contributing and we can adjust them to help with that.

Dr. Melissa Armstrong: And we know that a lot of medications, maybe you're doing well with them for a long time, but then as our body gets older, we don't process medications the same way. And so sometimes even though it's an old medicine that you seem to be doing well with, as we get older, side effects can develop even though it's not a new drug. And there are some drugs that you might use for some of the symptoms in Parkinson's disease, like urinary symptoms, that we know can have side effects on memory and thinking. So it really is important that your neurologist know all of your medications and all the things that you're taking over-the-counter.

Dr. Rachel Dolhun: And that you review them regularly. So every time you go in or every couple of visits that you're making sure that you review that list of things that you're taking. Steven, I want to turn to you about another very important part of maintaining your brain health, which is being social, interacting with others, having a support group. That's been harder for us, especially in the past year with the pandemic. But tell us how you've maintained your social connections, built a support group, and how that helps.

Steve Brody: Sure. I think the support group that I've been involved with is very helpful. It's a small group at this point, there are three of us. And every week, we get together and we talk. We talk about Lewy body or Parkinson's, not necessarily, sometimes we're just talking about our family or what TV shows are on tonight. But it's, I think, a very helpful interaction. And in fact, one of the participants, just as another example, is trying to get the group to learn a new language. And right now, it's between Spanish and Yiddish and maybe something else.

Steve Brody: But it's been, for me, a valuable experience to work with these people, to work with them consistently, to be friends with them. And so I really do support support. There are other things, obviously family is one, maybe the most important one is that we need to keep an eye on, particularly in stressful times, we need to keep an eye on our family relationships, make sure we're getting along with each other, playing nicely, helping out each other. And all that, I think, adds another level to what makes a meaningful difference at least in my life.

Dr. Rachel Dolhun: That's such an important point. That actually segues nicely into our next slide, which is some strategies whether again, you have cognitive changes or your loved one has memory and thinking changes, what can we do on our own and together to manage these? And speaking of communication, Dr. Armstrong, I want to move to you because you have such good tips on communication in this regard.

Dr. Melissa Armstrong: So this is something that I discuss a lot with the people I partner with in clinic, and that is having a good conversation. So we know that when you have Parkinson's disease, it can really affect multitasking and it can affect your ability to concentrate and to focus. Well, those are really important things when you have a conversation. And so there are strategies that we can use in Parkinson's to help make our conversations more effective and more likely to go well. Now you can't do this for every conversation in your life. But what I recommend, especially for the important conversations, is that we take out some of those challenges that come with the Parkinson's disease.

Dr. Melissa Armstrong: So when you have an important conversation, you're going to move, you're going to retire, there's a family issue, you want to set yourself up for success. So it should be a quiet room. There should be no distractions, no phones, no radio, no TV, no multitasking. That lets you focus just on the conversation. And then it should really be a one-on-one conversation, eye contact and focus. So we really get rid of the multitasking, it's just about this important conversation. And we really emphasize the ability to focus by having it be one-on-one, focused on a topic, the eye contact. And I think some of these tips can say, "We know these conversations and the multitasking is harder in Parkinson's. Let's make us more likely to have a really good conversation." You can't turn off your phone every time you want to talk, but for the important conversations, this can be really helpful.

Dr. Rachel Dolhun: And I think there are other tips to having more than one conversation. You don't have to solve everything in just one conversation. You can start the discussion and say, "We'll finish later." A lot of people find using humor is really helpful when discussing these tough topics. So if that sounds like you or that speaks to you, that's another way a lot of people find to be helpful.

Dr. Melissa Armstrong: And picking a good time of day. I just want to add picking... With Parkinson's, you may be better in the morning or better at night, even apart from the early bird, night owl, you may be on or off with your medication. So the timing of the conversation can be really important, too.

Dr. Rachel Dolhun: Very important. And Dr. Higginbotham, I want to ask you a question we commonly get. Are there treatments for cognitive changes, memory and thinking changes in Parkinson's?

Dr. Lenora Higginbotham: Yes, there are treatments right now. There's only one FDA approved drug right now to treat Parkinson's disease dementia. However, there are a couple of other ones too, that we will commonly use. So this medication is called rivastigmine as part of this class of medications called cholinesterase inhibitors. And that one can come in as a patch or as a pill. What I usually try to emphasize for patients who are about to start these medications is that in the trials, these medications don't necessarily turn around all cognitive deficits. What they are really skilled at doing or can be skilled at doing is masking cognitive changes in the future. So in general, what we would like to do is basically stabilize any cognitive decline going on. And while it doesn't change the biology, those medications can actually mask any progression.

Dr. Lenora Higginbotham: And so therefore, I usually tell patients if you're going to start a cholinesterase inhibitor, like rivastigmine or donepezil, or even memantine, which is a different type of medication out there that we use, I will ask you next visit, are your cognitive deficits the same? Or is your cognition the same? Or is it worsening? And if it's stable, that medication is likely doing its job, right? But also, these medications can give you a little bit of a boost. So I tell patients, anything that maybe happened, any declines that you've recently had maybe in the last six months or so, maybe a little bit longer, sometimes you can see a boost in those things that were recently declined. So these types of medications can give you a little bit of a boost, but also mask progression in the future. Only one of them is FDA approved, but we have some other ones.

Dr. Rachel Dolhun: And Dr. Armstrong, can you add in on, are there other things we can do aside? We've heard that there's a medication for some people, but are there other things, can we do brain therapy like we do physical therapy? Or are there other things we can add?

Dr. Melissa Armstrong: Sure. Well, I do always encourage what we talked about earlier, the physical exercise, thinking about diet. Some occupational therapists and some speech and language pathologists can do cognitive therapy as well. This is probably variably available to the people on this call. So not all speech therapists or occupational therapists have this training, and it can sometimes be variably covered by insurance, but there are therapists who are trained to help with the cognitive aspects as well. And we do engage the therapists at our center to help with those kinds of things. Some of that is strategies. How do you... You mentioned earlier the tip of the tongue syndrome. So our speech therapists will work with people for different strategies for how you either find the right word or move on to a topic. And so I do think whenever we think about symptoms in Parkinson disease, whether they're cognitive symptoms or other symptoms, we want to make sure we're coming from all the different directions. Is there a medicine that will help? Is there a therapy that will help? Will exercise help? What are strategies to compensate? And that's probably how we'll get our best outcomes.

Dr. Rachel Dolhun: A question from the audience which we commonly get is, does CBD help?

Dr. Lenora Higginbotham: There's no research that CBD or any compelling research that CBD is really effective for cognitive changes or motor changes in Parkinson's disease, or any associated symptoms. I think in general, CBD is suffering a little bit from an over-hyped phenomenon in general. It is slated out there. You'll see that it's promised to help with all these things. I think the most common one is anxiety. But actually, the data there is slim too. So it's definitely not something that I really push or recommend for patients to try for cognitive changes. Plus, it's expensive.

Dr. Rachel Dolhun: Your time and your effort might be better spent on finding a good exercise class or eating a good diet. But back to Dr. Armstrong's earlier point of making sure that no matter what you're taking, whether it's CBD or an over-the-counter medication, you're talking with your doctor. Because just because something is natural or safe doesn't necessarily mean it couldn't potentially increase symptoms or cause side effects. So always important to be in a conversation about what you're taking with your doctor.

Dr. Rachel Dolhun: Another question for you, Dr. Armstrong. What about deep brain stimulation, this surgery that we can do for Parkinson's symptoms? Can that help cognition?

Dr. Melissa Armstrong: So usually with what we have currently for deep brain stimulation, it's actually the opposite. We really worry about worsening cognition with the deep brain stimulation. We know that in people with Parkinson's who already have memory and thinking changes, especially when they're on the more severe end, the deep brain stimulation surgery has a risk of making that worse. And that's why for almost all the deep brain stimulation programs in the country, before you're considered a candidate for deep brain stimulation, they actually do memory and thinking testing, this neuropsychological testing, to make sure that memory and thinking aren't going to put you at a risk of more side effects.

Dr. Melissa Armstrong: There are a couple of small recent research studies that are using deep brain stimulation in new targets, not our traditional approved Parkinson targets, but new targets, to try to help memory and thinking. But those are really very early. They were done in very small groups and they are not ready for prime time. So there was some research about DBS for memory and thinking that really needs a lot more work. But for the deep brain stimulation we use right now for Parkinson's disease, we would not expect it to help cognition, and in some circumstances, it could make it worse.

Dr. Rachel Dolhun: And I don't want to leave this slide without talking about the care partner. So Steven, maybe I'll start with you and then move to you, Dr. Higginbotham. So Steven, you mentioned your wife being a big help with medication and other things. Are there tips that you have for the care partner or the loved one of someone who's living with changes in thinking and memory?

Steve Brody: One tip that comes to mind is, what if you have children whose parents have Lewy body or whatever? Is there a way to benefit from that relationship and make sure that it goes along appropriately? But I think what we need to do is we need to come up with age appropriate activities for the kids. For a kid who's eight years old, as distinguished from a kid who is 20 years old, you have very different abilities there. And so I recommend that as a tip that could be helpful.

Dr. Rachel Dolhun: And Lenora, you helped care for your grandmother who lived with Parkinson's and thinking changes. Anything that you experienced that you think would be helpful to others?

Dr. Lenora Higginbotham: Yeah. And just to preface it, my grandmother actually did end up developing Parkinson's disease dementia, and she had various symptoms of that disorder. So cognitive decline, also psychosis, which I think is really hard to deal with sometimes. So visual hallucinations, delusions, paranoia. And then one other thing we didn't really talk about with frontal dysfunction is over time, there can also be a little bit of disinhibition too. It almost looks like forgetfulness. But "Use your walker," you'll say, but they'll get up without the walker. These are things that are all due to the cognitive disorder that they have.

Dr. Lenora Higginbotham: And I try to counsel care partners who are in the office as well, is we all have this tendency to describe a lot of agency to the patient or our loved one. And sometimes if you just think about it a little bit differently, it can help you deal with it a little bit easier, become less frustrated. For instance, I was like, oh, she won't do this or he won't do that. But if you think about it as my grandmother's disease won't allow her to do this, or-

Dr. Rachel Dolhun: It's the disease, it's not them.

Dr. Lenora Higginbotham: Right. Her psychosis will not allow her to always get up with a walker. And therefore, that gets you to this area where we must supervise more instead of, we must tell them multiple times to do it, which is not actually going to be helpful.

Dr. Lenora Higginbotham: Another thing that I think it's really a tendency knee jerk to do is correct the patient, especially for things like hallucinations or delusions or things like this. No, that thing is not there. Don't worry about that. It's not there. But some of those tactics may work in some people, but other people may benefit a little bit more from redirection. So if they're looking outside at a person standing in the yard, redirect them to look at the dogs playing in the yard. Or if they're looking at their loved one in the yard and something troubling comes up, then redirect them to something comforting about that loved one. There's various ways to respond. Distraction is a good one, just completely bringing the attention away. And sometimes these other responses can be really, really helpful instead of that knee jerk, I just need to correct.

Dr. Lenora Higginbotham: And then the other one I just really want to emphasize is I often get patients' caregivers, and we went through this as a family, who are just really concerned about taking these transitions to assisted living or higher levels of care at home or these things that might cut down a little bit on the independence of the patient. But just to echo everything we said before, just communicate as openly as possible. It is going to be hard. There's not one right way to do it. But if you're communicating openly, you will get through it, I promise, and they will love you again.

Dr. Rachel Dolhun: And make sure that you get support for yourself. So when you're supporting someone else, when you're caring for someone else, it can be easy to put yourself second or last. And it's so important to make sure that you're getting support, whether it's from friends picking up your groceries or from an online support group where you can talk to others who are having similar experiences, that support is so important.

Dr. Rachel Dolhun: I want to move to our last slide, which talks about some of the research that's ongoing in this area. And we're certainly working on ways to diagnose. We talked about the difficulty of diagnosing these different conditions and figuring out how to diagnose, figuring out how to monitor. And along those lines, Dr. Armstrong, we got a question about how do you know, first of all, who might be more at risk for these changes? And then how they're going to change over time? Do we have any way to predict those things?

Dr. Melissa Armstrong: That's a great question. And I think some of that is a work in progress. And one of the challenges is what we discussed earlier, is that there is so much individuality in the experience of Parkinson disease. And so it's really hard. We want these generalities that we can apply from person to person and we're looking for those, but we also want to always acknowledge that Parkinson disease is really unique from person to person, and so everyone's experience is really different.

Dr. Melissa Armstrong: There are some things we know. So we know that when you are older, you are more likely to have some of the memory and thinking changes in Parkinson. They seem to be a combination of both how old you are and how long you've had the Parkinson's. So those two things together are two of the big, we call them risk factors, for when someone will start developing the memory and thinking changes. There are some genetic forms of Parkinson's that have more of the memory and thinking changes associated with them. We know that the older you get, the more likely you are to have Alzheimer disease changes too. You're not more likely to get Alzheimer's, we think, but it gets more and more common as people get older. And then from a progression standpoint, we know that if you have mild changes, you're more likely to have gradual worsening than someone who doesn't have any changes at all. But even with that, there's a lot of variability from person to person, as you heard about earlier.

Dr. Melissa Armstrong: We do want to make sure that we're addressing the addressable things, especially those medications that could be making things worse, and then reassessing over time. So one of the things I look for is what is the path that someone is following? And if they're following a slow path, things change slowly. They often stay slow unless some event happens. And if people are going more quickly, if the changes are going more quickly, then I often worry that they'll continue to be more quickly. So I try to use the individual as one of my cues as to what will happen for that person.

Dr. Rachel Dolhun: So making sure that you have, again, back to that close relationship with your doctor and your care partner, your family, so that you're in close communication about what's happening.

Dr. Rachel Dolhun: I can't believe we're at the end of the hour already. We got so many good questions. I know we got to some of them throughout the hour. But I do want to mention, we also have a very comprehensive guide on this topic, which we developed with people who live with Parkinson's and changes, their families, and with doctors and researchers. And you can find that guide to navigating cognitive changes in Parkinson's in the resource list.

Dr. Rachel Dolhun: I want to thank all of our panelists. Dr. Armstrong, Dr. Higginbotham, and Steven, you were so helpful, gave us so much great information. And we hope that this was really helpful to you in the audience. Thank you again so much for being part of our community and for joining us today. Mark your calendar for our next webinar, which is on April 15, where we'll talk about the different options and what to consider about participating in research. Thanks again, and have a great day.

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