

Michael J. Fox:

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Michael J. Fox Foundation:

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

Larry Gifford:

Hi, welcome to the Michael J. Fox foundation's Parkinson's podcast. I'm Larry Gifford, a proud member of the Michael J. Fox foundation, patient council, founder of PD, avengers.com and host of another podcast called when life gives you Parkinson's. I am excited because my podcast Powell, Rachel Dolhun, the SVP of medical communications of the Michael J. Fox foundation is here with me today. Hello, Rachel

Rachel Dolhun:

It's great to be back together, Larry.

Larry Gifford:

Oh my gosh. They can't keep us apart.

Rachel Dolhun:

You can't do we're a dynamic duo.

Larry Gifford:

That's right today we do have a sensitive topic. We're going to get into about cognition and we've got some great guests. We have Melissa Armstrong. She's an MD and MSC. So she is the associate professor and associate chair of faculty development director, university of Florida, Dorothy Ben-Gurion clinical research headquarters for Lewy body dementia, that's a mouthful. She takes care of people with Parkinson's and related cognitive changes. She's with the department of neurology at the university of Florida.

Larry Gifford:

And we also have Pamela and Dana bland. Pamela is a person living with Parkinson's and she's having some cognitive changes. She's 71 has, has Parkinson's for 21 years. She has been a nurse and an educator and she and her husband Dana live in the, in Florida, just outside of Gainesville. All right, so we have a full house. We have Dana and Pam and Melissa, and Rachel, welcome to the podcast. Everybody happy to be here. All right. So Rachel let's let's you and I start here you know, this is a sensitive topic. That's kind of hard to talk about. I want to make sure I'm respectful. Oftentimes I get a little goofy, so you got reign me in, okay.

Rachel Dolhun:

I'll do my best.

Larry Gifford:

Michael J. Fox wrote in his new book, a Parkinson's condition. I rarely contemplated before now, much less spoke of his cognitive change, loss of memory, confusion. What am I thinking? And how am I doing? And frankly, he speaks for a lot of us in the Parkinson's community that especially when it's first starts to happen. And you're like, Oh, is that Parkinson's or is that me getting older? And how do you notice the difference and how do you maneuver through that? So I'm going to start with you, Rachel, and we'll probably bring in Melissa, but like when, when do you know that it's actually a part of the Parkinson's disease instead of just old?

Rachel Dolhun:

Well, I think exactly, like you said, it's such a sensitive topic and it's so hard to talk about for people with, or without Parkinson's and people tell us so regularly though, that this is one of the things that they really worry about, that people with, Parkinson's worry about that their families worry about. And we sort of do a disservice by not talking about it. So as much as we can, you know, as comfortable as we can ever get with this tough topic, it's so important to talk about it. And that's why I'm so glad we're having this conversation, that we have people who are joining us to talk about their experience, because the more we can open up this dialogue, the better we can get at tackling these tough issues and having these regular conversations with loved ones and with our doctors who can help us along.

Larry Gifford:

So let's bring in Dr. Armstrong, Melissa, let's just start at the very basics. What is cognitive issues or cognitive decline or know a cognitive problem? How do you define the cognition?

Melissa Armstrong:

Well, and I talk about it in Parkinson's. I really like to use the term memory and thinking, because that really captures that when we, when we think about memory and age and thinking, we also often focus on that memory piece of it. But when we think about cognition, it's a lot more than memory. It is. How do we multitask? How do we pay attention to things? How do we understand where objects are in space? How do we use our phones? So when we think about cognition, it's memory and thinking,

Rachel Dolhun:

And so Melissa cognition or memory and thinking they can, they do change naturally with age, right. But then they also can change with Parkinson. So how do you know what's what?

Melissa Armstrong:

Well, that's a great question. And I think with, as with so much of Parkinson's, it can be hard to know for sure, but we do know that there are some things that happen commonly in Parkinson's. So multitasking. What I mentioned earlier is a great example. Parkinson's makes it harder to pay attention to things. It makes it harder to multitask doing more than one thing at a time. And so if someone tells me that they're noticing those changes, I'm pretty suspicious that they could be at least in part Parkinson related

Larry Gifford:

Dr. Armstrong I'm having those problems. Multitasking was a superpower of mine for so long. And now if I get distracted by one thing, it takes me like 15 minutes to get back on track. And I get lost in like these somehow, like, how did I get here? And what am I doing? Like, I lose time throughout the day and where I used to be able to knock off a list of 20 things. If I get three things done a day, I feel pretty good.

Melissa Armstrong:

And we can all have trouble multitasking at some times. But, you know, when you change from your super power struggling more, you know, we wonder if Parkinson's is part of that. Yeah.

Larry Gifford:

Pam, I'd like to bring you in here. Have you noticed this type of stuff?

Pamela Bland:

Yes, I have. I, I identify exactly. And it's, it's not always happening. Like we think it's supposed to happen. I, I can recall a point where I was scared to death because my phone wasn't doing what I wanted it to do. And I, I would have had the right now I'm having a problem with talking and it comes and goes, and I have to kind of go with it. But I have a partner who is very, very, how can I say he he's very much pay attention to everything I do. So he can tell me if I'm doing right or doing not doing right. And I appreciate that

Melissa Armstrong:

Parkinson's people can fluctuate how times where they're thinking or talking better and times where they're thinking or talking worse, what you describe as you know exactly what we see.

Rachel Dolhun:

What can people look for? I mean, is it medication wearing off? Is it not getting enough sleep the night before? Is it stress that kind of takes you on this up and down with the cognitive changes sometimes.

Melissa Armstrong:

So there is some of that that seems to be inherent to the Parkinson's. The Parkinson's makes you go up and down, but some people notice that they feel better after they take their medication mentally, not just physically. And they feel worse mentally when they're approaching the end of dose, if you didn't sleep well in Parkinson's, everything can be affected and medications, some of those over the counter ones can really have an effect, the most common diphenhydramine or Benadryl. It's an, a lot of those over the counter sleep AIDS can really hit people with Parkinson's hard confusion, grogginess. So it really is a combination of different things. Right.

Pamela Bland:

I think I noticed that they do grant on every medication. It, and it's happening again. I can't, he's a book talk for me because I can't talk her at all right now.

Larry Gifford:

You're doing great, Pam.

Pamela Bland:

Well, what do you have to say?

Dana Bland:

Everything contributes. Like she just doesn't sleep well. And a couple of years ago she lost, she was healthier, but she, her mother, our mothers were passing by basically about the same time and that stress level really kicked up. And it kind of made things much worse wouldn't you say Pam. Yeah. And then on my side, I don't want to tell her every little thing to do. I mean, she's a smart, intelligent one. I mean, she's, you know, she's in charge, but you don't want to fall down either. It's of where's the line that you're nitpicking and being helpful. I mean, that's kind of a boring line and my personalities, I'm not a very patient person anyway. So I need some modifications, I guess. I'm, I'm learning slowly.

Larry Gifford:

Dana, when did you first start noticing some cognitive issues with Pam?

Dana Bland:

Well, a couple of years ago, maybe slight, but yeah. Excellent fan. I started writing pennies. You take your, all the bills and I've been writing the bills now for a couple of years, they're like appointments, like I've noticed like like even this appointment today, she's still be confused. Why is it 11? O'clock no, Pam, this was at three o'clock, but we'll talk to you guys. And it's kind of, what do you think then it's confusing when you say a lot of things?

Pamela Bland:

They're confusing, confusing that weren't confused before

Dana Bland:

But yet you also want them to maintain their independence. So it's a fine line, I guess.

Larry Gifford:

Yeah. I find it gets very difficult if there's extra noise in the room or distractions, or like, if there's the TV on and somebody's talking to me and my son is over there doing, playing with the cars, I'm like, okay, we gotta have something else off. Cause I can't, I can't bring it all together.

Melissa Armstrong:

And that's one of the things I really talk a lot about in people I'm working with, with Parkinson's with some early changes, even when it's not affecting every aspect of your life, it's that multitasking and attention that can really happen early, but we really rely on that in day-to-day life. And so some of the early strategies I talk about with people are just what you say. If you have an important conversation, you know, you want to be in a quiet room, no TV, no radio, no phone, no kids, eye contact, really talking about, you know, if it's a work issue or a marriage issue or a family issue, making sure that you're optimizing the chances of having a really good conversation and to do that, you often need to strip away all those distractions.

Larry Gifford:

It's funny. Have you ever tried to cook dinner and you're slicing a cucumber and somebody asks you a question, no, stop slicing the cucumber to look at him to answer the question or, or like, I'll give him my wife, a foot massage and she'll ask me a question and I'll stop. And she goes, don't stop.

Rachel Dolhun:

But speaking of conversation, Melissa, cause you have some really good pointers there about, you know, talking one-on-one minimizing distractions, having a quiet room, all those sorts of things, talking about this, no matter if we get rid of all the distractions, isn't easy. What kinds of tips or strategies do you have for people to talk about this with their loved ones?

Melissa Armstrong:

Yeah, I mean, that's a, a real challenge and I think it gets to the point of how important it is for us to be honest in our relationships in general. And this really is in both directions. And this is to your point, Dana too, that, you know, it's hard, where is that fine line between you know, over and helping people's independence? You know, there's also that fine line of, you know, what do we talk about? How do we talk about it? Who initiated the conversation, some of that will depend on your marriage, but I do think it's important to be honest with yourself and people in your family about what you're struggling with, because that really gives an opportunity to figure out well, what could we do practically in day-to-day life to make this situation easier?

Larry Gifford:

Well, and one of the things that is really hard to talk about and really hard to, to do is to admit that maybe you're not the best driver that you used to be and that maybe your reaction times aren't the same as they used to be. And I know I've discovered that and my wife does all the driving. I take cabs to work or transit to work. And I, it's just not worth the risk

Rachel Dolhun:

Driving is a really hard one for a lot of people. It's a way that we have our independence. We can't around. We're used to doing what we wanted to going, where we want to go when we want to go. And especially if you don't have a good public transportation infrastructure in your city, it can be really, really hard to let go of driving. And so that's often a big thing for people and their families to talk about. When is the right time? What are the things we look for and, and how to go about switching from not to, to not driving?

Larry Gifford:

Pam, what's your experience with that?

Pamela Bland:

Well, Dana didn't really tell me I couldn't drive.

Dana Bland:

But the few times I passed Pam in town. I don't mean this meanly, I mean, her head's like locked on straight ahead. You know, when you drive, you have to kind of look around like a cat or something. I

wouldn't have a problem with him making the small trips or a couple blocks away or something, but I don't think you want to drive the temple from here.

Melissa Armstrong:

I think driving is a really good example of how when people live with Parkinson's, it's the physical and it's the mental. So we know that your physical ability can affect your ability to drive, but there's a lot of mental and driving to your point. Dana, you have to have that multitasking where you're looking all around. I mentioned earlier that Parkinson's can affect your visual, spatial reasoning. Where is your car? Where is the next car? Where's the curve. And so it's a really good example of how Parkinson's is complicated as physical and cognitive together. And those two things together make it especially difficult.

Larry Gifford:

And if you have the radio on and if there's people that are talking and if, you know, and, and, and

Melissa Armstrong:

Is one that needs a lot of conversation and it needs conversation between the person living with Parkinson's and the family and the doctor, because sometimes you really do need the doctor to be the bad guy there.

Larry Gifford:

Well, let's talk about that a little bit because the doctors will take away your driver's license at certain points. I think it's different from state to state country to country, but you know, w what's your experience with that Dr. Armstrong, as far as what, what, what would be a trigger?

Melissa Armstrong:

You know, there's some research that shows that none of us are perfect at predicting. When is the right time to start driving? There's a little research that says that families are probably the most accurate, but if I have worries based, usually it's based on the physical and the cognitive that I bring it up and discuss it. And I really emphasize that we want to stop driving before something terrible happened.

Rachel Dolhun:

Just to be clear Dr. Armstrong, you don't like physically go in their wallet and take their driver's license, because I don't want people to be afraid that you know, their doctor one day is just going to say, hand it over. You know, this is a, this is a conversation, and this is something you're doing in the best interest of that person, you know, do no harm, right. That person and their family.

Melissa Armstrong:

Yeah. And it's not usually like a moment. So often as Parkinson gets more advanced, we'll start talking about, you know, how his driving going. So I'll ask that at every visit to get a sense, and also so that people are watching it. And then if we start to get worried, if you had to fender benders since the last appointment, then we'll talk about, well, what is the best approach for you? You know, I'm worried because some of what I'm hearing sounds like the Parkinson's is affecting the driving. I don't want something really bad to happen. How do you feel about giving it up? And if they're willing to, you know, they have a spouse who can help they're in a safe place where there's public transit, and they're willing

to say, look, I'm willing to, to stop. Now. Then we'll go. That route of the person with Parkinson's says, this is really important to me. I depend on this. I want this. I don't want to give this up. Even though my spouse is worried, I know I'm a safe driver that I say, you know, I don't know. You don't know why don't we have an evaluation, but it's a process. It's not a moment. And there are lots of conversations and discussions about it.

Larry Gifford:

What are some other things that people may experience as their cognition declines?

Melissa Armstrong:

Sometimes we do talk about memory and the memory problems in Parkinson's are different than memory problems that can happen with some other diseases like Alzheimer's disease. So in Alzheimer's disease, which is totally different than Parkinson's, you have trouble making new memories. So you might not remember what happened in the morning, but in Parkinson's you can usually still make that memory, but you have trouble getting at it. And so people with Parkinson's can often benefit from cues or reminders because the memory is there. You just need some help to get at it. And so those can be useful strategies for people with Parkinson's.

Larry Gifford:

I feel oftentimes when I'm telling a story, it's more like charades. I'm like, it's like guide, it looks this with the thing and the ears and the, and then my wife will go, Oh, Joe. So Joe,

Rachel Dolhun:

It's important to stress too, that it's like, everything in Parkinson's is different for different people. And so, you know, one person might have a lot of that word finding difficulty. Another person might have, you know, more changes they noticed with attention. So it's different for different people. It depends on your situation, your work, your, your life situation and that sort of thing. But there's also Melissa, maybe you can tell us a little more, there's really a broad range of changes that can happen in Parkinson's. So it can be from the most mild, you barely notice that we just caught it on our testing that we did in the office as doctors to much more significant, where it really impacts our daily life.

Melissa Armstrong:

That's absolutely right. And it's a gradual thing. So it's not something people usually notice overnight, you know, it can start subtle, you know, ah, I can't remember that darn word, you know, then it gets a bit more prominent, more trouble multitasking. And just like the movement problems of Parkinson's the mental, the cognitive problems can gradually get worse, but usually it's slow. But if you live with Parkinson's long enough, it can become a bigger and bigger problem until it's really affecting everyday life. And so we, we, you know, we call it normal thinking and then there's this mild cognitive impairment stage where you're noticing changes your testing, isn't normal, but you can still do most of what you need to do. And then diminish it is the medical word that says your memory and thinking have declined enough that it's having a major impact on day-to-day life. And that happens in Parkinson's too.

Larry Gifford:

Pam, when I was telling my story, I saw your head shake and that feel familiar to you playing charades when you're trying to have a conversation.

Pamela Bland:

Yes, I do that all the time. And Dana, he does it.

Dana Bland:

So I tell her you have to give me a better, more clues.

Rachel Dolhun:

Good point too, Larry, because you mentioned something about how, you know, if you're tired it's yes or no questions, or it's one of two choices that sort of don't give me open-ended question

Larry Gifford:

After 4:30, no open-ended questions

Rachel Dolhun:

This balance, again, back to that conversation back to figuring out there's a lot that your care partner or your spouse can really help with as far as moving communication along,

Larry Gifford:

What are the best techniques for, for a spouse or a partner to support their loved one?

Melissa Armstrong:

I think that that probably varies a lot from person to person and relationship to relationship. And just like, you know, everyone with Parkinson's is really unique and the experiences, there are a lot of differences between different marriages. And I think that affects how people with Parkinson's and their spouses relate, or how people with Parkinson's and their kids relate. So I think some of those communication strategies are born out of the relationship that you already have. I do think it's important for, you know, family and friends to be patient, you know, so when those words aren't coming, don't add to the pressure, you know, wait, let it come. Things are slower in Parkinson's and allow space for that being supportive, being helpful data, to your point, you know, finding that narrow road of being helpful, but not over-protective, that's not a single answer, right? It's not like you, like, you know exactly what that is. That's a bit of a moving target

Dana Bland:

And it keeps chase like chasing smoke. You heard it from, am I doing this right? Or maybe I'm maybe I'm doing too much or too little. You never know.

Melissa Armstrong:

And you know, Parkinson's, we just talked about it changes over time. And so, you know, what, what the best way to support today, it may be a little bit different in three months or six months or a year. And so it's, it's constant readjustment.

Pamela Bland:

We've been married for 35 years, I think. So it is changes all the time and it doesn't always get better, it's just, it's different.

Rachel Dolhun:

And one of the things we can't neglect to mention as a care partner is taking time for yourself. I know we always say it. And it's one of those things it's so much easier said than done, but Dana, talk a little bit about how, how you do this, how you manage time away, but also still taking care of Pam.

Dana Bland:

I live in a great spot to be outside. And a lot of my friends, we cycled riding bicycles a lot, not enough, but so I'd like Tuesday night is bike night. So we've got rod, a microphone and a half and pencil and we'd go all, go have something to eat. And it's good. It's mainly teased out, used to be Tuesday, Thursday, Friday, and Saturday, but that's, you know, so things have kind of dialed down, but it's still good. And you have to get away. You have to find your peace. I was out last Tuesday night and I was going along. I'm trying to erase the day. You're just trying to clear my mind, feel better and feel, you know, it feels good to get outside.

Larry Gifford:

Yeah. Outside. So really I think a great thing. My wife goes on hikes in the morning. She'll drop off Henry at the school and then she'll stop and go for an hour long hike, just so she can have her me time before she dives into the day. And I think that's really helping her a lot just sort of have her space and timeless, do a podcast or call a friend or, you know, and I'm real supportive of her doing different workshops and stuff that she wants to do or go out with her friends and it's ever changing. It's funny. I was thinking about what Dana and Pam were saying about how communication after 30 some years is, is changing. And we've been married 21 years. And there are some days where it feels like we've been married six months. Like we are just not on the same page at all. Like the old communication things that we like. We, we could just look at each other, know what each other was going to say. And now we are so off base. Sometimes it's, it's so frustrating because it's like, well, three years ago we were fine and now we're not even on the same street, let alone in the same house.

Larry Gifford:

And we're like, we'll just take a break. I'm like, okay, this is not working right now for whatever reason, we'll, we'll revisit this, but we do. We, we are both communicators by trade. So we, we talk a lot and we're very honest with each other. And we have that sort of the brave space where we can tell each other things that are hard to tell each other, without there being a reaction or a, you know, it's like, this is the time where we're going to talk about this and it may sting, but breathe through it. And then let's talk about it.

Melissa Armstrong:

When we talk about, you know, care partners taking a break, I think it's important to acknowledge that there are, you know, when Parkinson's really starts to affect memory and thinking severely there are going to be people with Parkinson's and memory and thinking problems, who can be at the point where they cannot be safely at home alone, but it's still really important for those families and caregivers to get a break in those circumstances, but you have to be more creative so that can involve having family members come over for an afternoon or an evening, or someone from church coming over to share a lunch, or sometimes it means hired caregivers. So it gets more challenging when the person with Parkinson really shouldn't be home alone, but it's still a really important thing to figure out

Larry Gifford:

Wondering, is there any way to is there medicine, or is there any activities that you can do to strengthen your cognition? Like can, can you go back the other way once it starts going downhill?

Melissa Armstrong:

Well, I think there are some things that the research supports that we can try to help. There's not too much in Parkinson's that goes backwards, but there are still many things that we can do. So physical exercise is really important and there is more and more research showing the physical, the benefits of physical exercise and Parkinson's, and a lot of that research is about, you know, the physical part of it. But there's some research that suggests that physical activity can help thinking too in Parkinson's and outside Parkinson's. So I do think that physical exercise is important. We do usually encourage quote, unquote, mental exercise, staying mentally active. I'll say the research is a little bit more divided on that, but it isn't probably going to hurt you. And so staying mentally active in many different ways is something we often encourage. There is one FDA approved medication for memory and thinking in Parkinson's it's called resisted mean. And I would say we do often use that when the memory and thinking problems are more severe, but it's not a miracle pill

Rachel Dolhun:

Diet too, because people always ask about diet and it is, you know, this is advice nobody wants to do, right? Eat well, exercise, sleep more, you know, it's, it's hard to do.

Larry Gifford:

Bring it on, I like restrictions.

Rachel Dolhun:

But the Mediterranean diet, which is kind of more fish, less processed, less sugar, less like we usually eat as Americans. That's going to be the thing that's going to support your heart health, your brain health, your overall health on this topic. You know, we mentioned exercise, we mentioned socializing all of these things that are so important for general health and for brain health. But we have this pandemic going on, which has really limited our ability to exercise together, to meet in person. So Melissa, maybe we can start with you on and how you've seen what you've heard from people as far as how the pandemic is affecting these activities and, and even memory and thinking.

Melissa Armstrong:

So we have definitely seen at our center that the pandemic has had a real hit on people with Parkinson's both physically and mentally every day that I see people with Parkinson's and their families. I hear about how people really feel that they've worse and physically and worse than mentally. And we think that is probably because of decreased exercise, staying home, more, less socialization, last activity. It's really effecting people's physical and mental health, as well as their wellbeing.

Rachel Dolhun:

Maybe we can start with Dana and Pam and then Larry, you can tell us, but w what have you done to stay active, to see your family and friends and those sorts of things during the pandemic? What has helped you along?

Pamela Bland:

I think for Dana we all are. He loves to ride a bike and I'm gonna get on mine. I just haven't done it yet because it's either too hot, too cold

Dana Bland:

Or you need a new knee.

Pamela Bland:

Well, I got a new knee. I got a knee replacement spent several months ago and that's good, but now I have to have the other knee done. So but I'm gonna do it. I'm gonna do more exercise that, but when you don't feel good, you know, you gotta get out in the sun and run or whatever you're doing.

Dana Bland:

It's hard, but, you know, and if you find yourself, we're talking about our Tuesday night thing, our friends from Canada and Vermont that come down this way, we're in Florida. So it's a real seasonal state. No, one's coming down. Everyone's scared to go out, to eat, grow up in our sixties and seventies. So it's really put a crimp on our social life. Everything's changed, you know, you're scared to do anything, but you can't remain totally isolated.

Rachel Dolhun:

And we rely so much on technology now, right? On the zoom calls or on FaceTime or whatever it is. But that's not so easy though.

Dana Bland:

Yeah. The, the phone is a big issue for Pam and that, you know,

Pamela Bland:

I try.

Dana Bland:

She tries to you know, I'm not, I want to remain patient as I can, but you know, it's like eating well, if I'm at work all day and come, when you go to the store, let's not go to the store, let's have a frozen Pizza. Let's not want, let's just have another beer. You know, I've often wondered what effect Parkinson's has or any major illness or age, whatever has some caregivers.

Melissa Armstrong:

Yeah. I think people cope with caregiving in different ways. And there are good ways and bad ways. And I think it really supports or speaks to the need for a good support network, you know, to, to help you cope with what life throws at you, you know, your own health, your own life, because it's so complicated.

Pamela Bland:

We have great circle of friends. We just can't see them

Melissa Armstrong:

No, and that's a good point. It depends on what affects, not just the person with Parkinson's and trouble exercising and getting out and socializing, but that has a huge effect on caregiving, harder to bring people to your house safely, to give you the break for, for caregivers who need someone there 24 seven, that's been a huge challenge. You don't want to bring in strangers. You don't want to bring in people who aren't isolating. And so that really speaks to the effect that COVID has not just on the person with Parkinson's, but on the whole caregiving experience too,

Dana Bland:

We'll go to the store. And I said, well, Pam, I'll run in. You sit in the truck. I'm sure she'd run. You know, if it wasn't COVID, she would like to scroll down. We eat a lot better when she's untethered shopping than a frozen pizza. I think Pam is very fortunate to in this experience 20 years, and we're fortunate to live close to the University of Florida. People are taking great care of us and you know, everyone's working hard. This is a challenge, but it's we're fortunate to have such great support. Yeah.

Rachel Dolhun:

You have a great attitude, which, which goes a long way, that optimism and keeping positive, where you can keep positive, but you also have a good team. It sounds like you're a good team, but you also have a good team of care professionals around you. So your doctor, who's helping you manage that. You know, an occupational therapist can help you with some things around the house and certain activities and a support network, whether that's your friends or chatting online with other people who have Parkinson's are care partners to people with Parkinson's. So building this network and this support system around you is critical. We talked a lot about what you can do to kind of boost your brain health and stay healthy, eat well, exercise, socialize, all these things. But Melissa, if we can talk a little bit about what research is ongoing to get us better treatments, better tests for cognitive changes in Parkinson's.

Melissa Armstrong:

Sure. Well, I think, you know, one of the challenge of Parkinson's, but also one of the exciting things is all of the different kinds of research going on in Parkinson's. And so when we think about research in Parkinson's, researchers really are coming at it from all different directions. So when we think about memory and thinking, there are researchers, we call them preclinical. So clinical would be working with the patient, but this is more someone working with a lab trying to figure out, well, what exactly is it about Parkinson's that is causing the memory and thinking changes? What parts of the brain are involved? Chemicals are involved because we know it's not just dopamine. We can give you more dopamine and maybe help you physically, but that doesn't always have a huge impact on your memory and thinking, so those preclinical researchers are trying to figure out, well, what should we target if we want to improve memory and thinking what's happening in the brain with these problems.

Melissa Armstrong:

And then there are different drug studies, like you mentioned, and they're really looking at it from again, different directions, different chemicals. So I mentioned earlier, the river stigma in that is FDA approved for use that targets acetylcholine, which is one of the chemicals in the brain. But some of the other drugs that are people are looking at are looking at dopamine. If we affect opening in different ways,

could we affect memory and thinking if we affect the brain chemical serotonin, could we affect memory and thinking? So kind of coming at it from different directions to see what we could help. Then we want to think about non-drug strategies, diet, exercise, mental exercise, socialization, how can those non-drug strategies help memory and thinking? And then we still need to learn more about what is the experience of memory and thinking when that starts, what should we expect to happen so that we can tell people what they should expect to happen? And so we really do need to come at it from all of these different directions so that we can have different solutions.

Rachel Dolhun:

There's so much work as, as you talked about so much happening in this area, which is really promising and hopeful.

Larry Gifford:

What would you like people to know about cognitive changes? Pam?

Pamela Bland:

I would like them to know that it's not a bad. It just has to keep plugging along. Yeah.

Larry Gifford:

I think a sense of humor comes in handy.

Dana Bland:

I keep thinking about this sometimes. I don't know, you know, Parkinson, my impression is a disease. You didn't do something like smoking at lung cancer. You didn't, this disease chose you. It didn't, you didn't choose it. If that makes any sense, you know,

Larry Gifford:

Maybe not consciously, I don't, I was never given that choice

Dana Bland:

Pam wasn't either maybe you can eat right. And live, you know, the right. And still come down with product is not, it's not an action reaction.

Rachel Dolhun:

People with Parkinson's have said before, I didn't choose Parkinson's. I never would choose Parkinson's, but I can choose what I do with it. Right. And it sounds like you're sort of living proof of that.

Larry Gifford:

I want to thank Pam and Dana for, for being here and being in this brave space with us to talk about this. So you're, you're such a great example for so many people. So thank you for being here

Rachel Dolhun:

And you too, Larry.

Larry Gifford:

Oh, thanks. Rachel and Dr. Armstrong. We really appreciate your insights. So this was a, this was a great conversation and I know I learned some stuff here and I hopefully have other people took away at least tidbit or two that they can apply at home.

All:

Thanks for having us. Thank you so much. All right.

Larry Gifford:

Before we go, Rachel, I'd like to really dive into some other resources at the Michael J. Fox foundation may have people who are looking to learn more about this.

Rachel Dolhun:

We have a lot of materials on this topic. One is a guide on cognitive changes in Parkinson's. It has strategies on how to boost your brain health, how to manage these changes, how to talk to family members and your doctors, how to build the right care team. It's a really comprehensive guide on this topic for people living with Parkinson's and their families. We also have an asked the MD video and various blogs on the topic as well.

Larry Gifford:

Well, well, Rachel, thank you for your time and your experience and your insights and your knowledge and your laughter because I always like it when you laugh at my jokes.

Rachel Dolhun:

And they don't pay me to do that either.

Larry Gifford:

No, no, there's no extra dollars for that. And we do want to thank Acadia pharmaceuticals for helping to support this episode of the podcast for everyone at the Michael J. Fox foundation, who is here until Parkinson's isn't. Thank you for listening. I'm Larry Gifford. You can follow me on Facebook, Twitter, and Instagram. It's the same handle @Parkinsonspod. Be well, we'll talk to you next time.

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