



## Davis Phinney Foundation Parkinson's Care Partner Training

### Session 2: Managing Change, Stages, Falls, Exercise, Constipation, and nOH

Davis Phinney Foundation

*Note: This is not a flawless, word-for-word transcript, but it's close.*

Polly Dawkins, MBA (Executive Director, Davis Phinney Foundation):

Hello, everybody, and welcome to our second session or third session of our care Partner training program. I'm Polly Dawkins, executive director of the Davis Phinney Foundation, and I'm here again with Dr. Jori Fleisher. Hello, Jori.

Jori Fleisher, MDS (Associate Professor of Neurological Sciences, Rush University Medical Center):

It's good to see you. I'm good. How are you?

Polly Dawkins:

Good. So, here are some universal questions that were asked last week. Question for you, Jori.

Jori Fleisher:

Yeah.

Polly Dawkins:

How do I deal with my person with Parkinson's if they don't want outside help and don't seem to think they have limitations? Do you have some thoughts on that?

Jori Fleisher:

I think it's a universal question, and I think sometimes,

Melani Dizon:

So really sorry, really quickly. There's a distinction there. It was not that they have limitations that they, that the person with Parkinson's doesn't understand that the care partner has limitations to what they're able to provide care. Like how do they deal with that?

Jori Fleisher:

Oh, that's a different question and also great, and sorry for the background noise. I'm in Chicago, and that's the pink line, which is apparently rush hour right now outside of my window. I mean, I think recognizing, right, that we can only do what we can do. So, it sounds like this might be someone where the person with Parkinson's who recognizes the challenges or limitations that they have and is asking for help from their care partner, and the care partner is doing everything that they can, but there is a limit to that, right? So, everyone has a limit. And everyone's limit is going to look different, right? So, I have some care partners where, you know, their loved one needs help moving their legs up and down, you know, off of a bed. And the care partner themselves has really bad back pain, right?

So, recognizing and saying, I would love to help you. I can't; that's not safe for me. And talking with your healthcare team about do we need a sit-to-stand device. Do we need leg lifters? Do we, you know, is this where we would bring in a paid caregiver to try to help with certain tasks? So, being really honest, and we talked last week about, you know, caregiving is coming from a place of love most of the time. And so, recognizing, you know, if I can't do something for you, it is not for lack of wanting or trying; it's because here is the challenge. So, how can we troubleshoot around this? And problem-solving together, I think, is really helpful. You know, sometimes there's the, you don't want to say no, you could say yes if, right? Yes, I could help you do your physical therapy exercises if I can do them sitting down or, you know, yes, we can have that extra serving of a suite or something else that maybe you're not supposed to have if we do an extra walk around the block, and maybe you could do that with so-and-so. So, I think it's looking for those creative solutions, but acknowledging that it is okay to recognize the limits first.

Polly Dawkins:

Great approach. Another universal question that was asked is, how do I deal with the pain I feel when imagining the future?

Jori Fleisher:

Oh, I think that's so hard. I think just number one: shout out to the person who wrote that because it takes so much courage even to put that into words. I think holding that right sometimes I've heard from people that, you know, we get so worried about feeling a specific emotion, feeling the grief, or feeling anger that we try to push it off. And if you actually just kind of sit and name that feeling that you're feeling, is it worry? Is it anger? Is it disappointment? Sitting with that for a minute to say, here's the name for this thing that I'm feeling can actually make it easier to kind of process and get through. So, if you've never seen it, there's something called the feelings wheel. I didn't know about this until recently. You know, kids learn in preschool, happy, surprised, sad.

There are dozens of feelings. There are great words for feelings. So, sometimes just looking that, you know, looking for that and going, oh, you know what, this is what I'm feeling. And

we're going to talk about that sort of anticipatory grief and the ambiguous loss of this is not how I thought things would go. And I believe the person who coined the term for ambiguous loss, her name is Pauline Boss. So, I would shout out, you know, looking up anything that she's written on that topic, talk with other care partners who may be, you know, coping with this in similar or different ways. Talk with your person with Parkinson's because they may be also coping with this in adjacent similar ways, right? And I think to be able to acknowledge it together and say, well, we thought we were going to be able to do this, right? Sometimes that's a trip, sometimes that's, you know, a certain activity we thought we could, you know, hike in Patagonia, and do the following thing. Maybe it's not that we can't; maybe it's that it looks different. Maybe it's a shorter trip. Maybe there's assistance, maybe, you know, whatever that is. Maybe retirement looks different, but that doesn't mean it can't still be filled with joy and find, you know, positive meaning in it. It's acknowledging that it's different and then working through it.

Polly Dawkins:

Thank you. Yeah. Another question that came in from many people is what if I because we talked about advocacy a bit last week. Yeah. What if I try to be an advocate, but my husband or my wife's care team never responds, or they're too busy, or they don't really know the answers? Yeah. And you get the barriers. Well, how would you answer that, Jerry?

Jori Fleisher:

I think there are a couple of answers. I mean, number one, my gut answer is you should always feel like your voice is heard by your loved one's healthcare team and by your own healthcare team. And there are so many barriers right now in healthcare, like we talked about last week, we're understaffed, and there are shortages in all this, but none of those excuses are being heard. And if you're advocating and you feel like you're not being heard, it might be, you know, that you might be sending paragraph-long messages in the electronic health portal. There isn't time for your healthcare provider to actually go through that and respond. It just there literally isn't time built into anyone's schedule for that. Right? So maybe it's at the next appointment saying, if I have concerns that come up between visits, what's the best way for me to communicate those to you?

Is it I need to schedule another visit where we just talk about those things? Is it that you want it in a message? Is it that I'm sending stuff that's too long, too short, too detailed, not detailed enough? I think, you know, having that open line of communication and asking will help because healthcare providers went into it for a reason. They want to be able to help. And most people, if they don't know the answer, want to help you find the answer, and get you to someone who can answer the question. And all of that said, if you feel like, yes, I've done that. I've tried and been asking; you are always entitled to a second opinion. I say this knowing that, you know, if the concern is with your movement disorders neurologist, there are not enough of us out there.

So, it's easy for me to say, go find another one. And that might be a year-long wait in some places, right? But getting your name on a list may at least give you that peace of mind of, I will get another opinion. Right. Talking with people in support groups that you're in or communities to say, who are you seeing? Do you like them? What, you know, what's their response time? It's kind of like using your network. Tap into that network. And I was told by a mentor at some point, anyone who says, you shouldn't get a second opinion on my opinion, you should definitely get a second opinion, right? Anyone who is so a hundred percent certain that they know all the things you just can't, in medicine, you can't. Day one of medical school, at least back in 2004, they told us 50% of what we teach you in the next four years, 50% we will have proven wrong. Ten years from now, we just don't know which 50%. It's

Polly Dawkins:

Wow.

Jori Fleisher:

So, everyone is on a continual, sort of lifelong learning in medicine. And so, if you think something just doesn't feel right, say something, I'll find someone else.

Polly Dawkins:

Yeah. I think many of us grow up with thinking that our clinicians, our physicians, are a bit a bit like God, right? And it, you have to take the word, you can't question it.

Jori Fleisher:

You should question, you should ask. Don't believe everything that Uncle Google tells you. But and I used to say Dr. Google, but I had a fantastic, amazing patient who one time I said that, and he goes, no, no, no, no, no. You know what, Thanksgiving, there's always an uncle sitting at the far end of the table, many conspiracy theories; you invite him, you listen, but you don't pay so much attention. This is Uncle Google. And I thought, yes. So, take that for what it's worth. But you know, Uncle Google is not a great source of medical information that's super trustworthy. But if you feel like you, you know, are questioning or your healthcare providers are not giving you answers to the questions that you have, you know, if when there's time right, then please, please reach out. You know, please try to find someone else who's a better fit.

Polly Dawkins:

Right. Great. Is it today we're, we're going to switch into our topics for, for today's session, which I mentioned earlier, managing change falls, exercise, constipation, and oh, neurogenic orthostatic hypertension. For those of you in the chat, I see you're very active, you're asking some questions, and you're chatting with one another; feel free to continue to do that, and

we'll get to those questions that are applicable today. All right. Before we get into managing change, Dory, I think it would be helpful to review a brief description of the stages of Parkinson's. We get questions about the staging of Parkinson's, and as we're talking about changing stages, it'd be helpful to know the baseline.

Jori Fleisher:

Absolutely. So, I'm going to give you sort of where we are today with staging and then a little bit of a foreshadowing of what might change soon in the future. But we're not there yet. Okay? So right now, today in Parkinson's, the staging system that we use is something called the Hone and Yak staging system; doctors Hone and Dr. Yaa came up with it, and we named it after them. Sometimes, people will call it H and Y or h y stage. It's all the same. There are five stages based on this system: 1, 2, 3, 4, and five. And it seems like, well then, you know, they follow after each other, which they do. But they're really, I want you to think of the more like categories. It's not like the change from one to the next is almost the same distance almost. And the other big caveat to this is, you know, we're going to talk, even today, we're going to talk about symptoms that are not movement symptoms or motor symptoms.

We're going to talk about some non-motor things. Later on, we're going to talk about hallucinations and, delusions and neuropsychiatric things. The staging system for Parkinson's, the Hone and Yak staging only takes into account movement symptoms including balance. Okay. So, you could have severe symptoms in some, in one of the other domains, and it has nothing to do with your stage. And you could have, you know, really severe movement symptoms, but limited other issues, and you'd be at a more advanced stage. Okay. So, what are the stages? So, stage one symptoms on one side of the body only. And by that, I mean when you see a movement disorders neurologist, and we do the taps and the collapse and the wiggles, and we move you all around other things, we can only find symptoms. You might, you know, barely depending on what you're feeling. But we are saying nope, no matter what we do, no matter how much we try to get a tremor or stiffness or slowness to sneak out, we can only find symptoms on one side of the body.

And I'll put out there that while that is stage one for a lot of people, by the time they notice symptoms, and they may only notice symptoms on one side of the body, but they may come and be diagnosed and already be a stage two. At that point, that's the norm. Because for most people, the symptoms are slow, so slowly insidious. They sneak in over the years and can be so subtle that you may notice some stiffness in a shoulder or a tremor or dragging a foot. But like I said, I think last week, movement disorder, neurologist, we are not good at parties. We're very distractible by watching subtle things about how people move. Right. So, we might see something on the exam that has not necessarily made it to your level of awareness, and that's okay. We don't want it to bother you.

Right. So, stage one symptoms, are just on one side of the body, and stage two symptoms are now on both sides of the body. Usually, the side that started having symptoms, which for most

people is their dominant side. But not everyone. The side where things started will always be the more affected side. In stage two, both sides involved, be asymmetric, but balance and posture are still okay. Maybe a little bit of astute posture, but we can correct it when we think about it. Stage three is sort of this moderate stage where both sides of the body are involved, and posture or balance are starting to get involved. So, if your loved one has movement disorders, a neurologist or their neurologist or someone checks their balance. So, we often do this terrible test called the pull test, where I stand behind someone and I tug them back from their shoulders.

It's not supposed to be a trust fault. I appreciate people's trust in me, but what we're actually testing is their reflex there to catch themselves. If someone brushes up against you going the other way on the sidewalk, will you take that step back and catch your balance? Or will you kind of take a stagger, or will you fall? That's what we're testing. And if someone has symptoms on both sides of the body as falling or they kind of staggering backwards or can't catch themselves on that test, you've made it to stage three, right? The day before, you might as be done fine on the pull test. I could be testing you on a bad day, and you don't do great on the poll test, and the next visit, you do better. So, all of that is to say someone can literally be a stage two, one day a stage three, the next and a stage two the following week.

It really kind of hinges on that balance issue. And that could depend on sleep, mood, medication, timing, all of that. So, just that caveat of if you change from a two to a three, know that could be situation-dependent and is not a huge deal. Okay. Stage four means symptoms are more moderate, involving both sides of the body. Posture is involved, and in order to walk, a person is still able to walk independently, but they need some kind of assistive device. So, a cane or a walker they might be able to kind of cruise from piece of furniture to piece of furniture for a small amount of time, but it is not recommended. Okay. But in order to go decent distances down a hallway, they really need an assisted device to be safe. Stage five means that the person is dependent on a wheelchair or bedbound unless assisted by another person, you know, usually a person or two or a person and an assisted device place. So, joy, yeah.

Melani Dizon:

Can I just chime in real quick? Because this is an important question, I think other people will have. Is the scale based on pre-medication, or they're not on medication, or they're on medication?

Jori Fleisher:

So that is a great question. So, most, I won't speak for everyone, but most of the time, we don't want people coming in on medicated unless we tell you to for some reason. Sometimes if people are undergoing evaluation, like before surgery, for example, your doc might say, come in without your meds. But otherwise, we're examining people usually in whatever state they

come to us on. So, often we'll say, when did you last take your meds? Do you feel on, do you feel off? And so, we can stage someone whatever point we're seeing them. So, someone might be a stage three off and stage two on. I have plenty of times in the office where people will come to me, they're coming to the end of a visit, I do their exam and they're stage three, and then the meds kick in and they go to walk out to check out at the front desk.

And I'm like, no, well look at you now. Okay. Right. And so, we're sort of in the middle there is a slightly, the newer version of the honing yard. The modified honing yard staging system has a stage 2.5, nothing else has a 0.5. And that 2.5 is kind of, that person is balances, you know, sort of just balancing on the edge there. So, sometimes clinical trials for someone to be enrolled might say specifically they need to be a stage three or lower in the on state, or they need to be a stage four in the off state, but stage three or better in the on state. That's a great question.

Polly Dawkins:

And so, if the staging is so situational or is dependent on, on the situation and doesn't take into account any of the non-motor or cognitive or other symptoms, why is staging in important of part of the diagnosis or a part of the visit?

Jori Fleisher:

That's a really good question. So, I think to some extent it's helpful for prognosis, for thinking about what kinds of things tend to go along with that stage. But like so much else about Parkinson's, there's so much variability, right? And so, seeing someone at stage two, they might say, you know, how long am I going to be like this? Right? Or how long am I going to be in this phase? And the literature is really variable on, you know, how long do people spend in each stage? And I've had folks who are, you know, currently really stage two and have been so for 30 years right? That's super unusual but not impossible, right? And so, they throw off the average. But I also have folks who come to me and I'm seeing them for the very first time and they have not been diagnosed, but they're coming in and they might be at stage four, right?

And whether their symptoms have been blamed on, well this is just old age, no. Right. Or this was something else, or it's just, you know, they've, they've been really estranged from care. I don't know how long they were at stage three or stage two before that. So, I think it's helpful for prognosis, but you know, I always caution folks, like if you're asking what stage am I at? What's, what is your hope? Like what do you hope that will tell you? recognize that it is not, there is not a timestamp on each of these stages, and there is not a guarantee of here's what this will look like. It really is, here's where you are mobility wise, right at this moment when the doctor examined you.

Polly Dawkins:

Okay.

Jori Fleisher:

So, and there's exciting work for so long. People have been asking, you know, when is there going to be a better staging system that we can say, you know, this is what this means, right? And it takes into account all of the other things. So, the good news is there are brilliant people within the Parkinson's world, all across the world who have been collaborating on a new staging system. And it takes into account not just the motor symptoms and the cognitive symptoms and tries to kind of skirt this difference between Parkinson's versus dementia with Lewy bodies versus Lewy body dementia, which is a mess. But also, as we've been discovering new biomarkers, so blood tests, spinal fluid tests, other things that we can test for that tell us something about what's going on in a disease underneath trying to say, okay, if someone were to get this test and have this result on this test, what does that mean in terms of staging?

What is, you know, trying to put some of these early things that we might actually even detect before someone has symptoms. Right? And the reason behind that, why would you even know that right? Is the ultimate goal being a cure, right? To get to a cure is so much more complicated scientifically because this disease is so variable. And because for many people, by the time they have symptoms, tremor, stiffness, slowness, that leads them to go seek medical care that leads to a diagnosis, you've actually lost 60 to 80% of the dopamine producing brain cells that you had before. So, glass half empty. Yeah. Right?

Glass half full. Your brain is amazing and can compensate tremendously even despite those losses, right? But what we want is to be able to pick someone up way before these, they've lost those 60 to 80% and say, you know what? You have no symptoms right now, but based on X, Y, and Z, you are at risk of Parkinson's, or you are at stage zero, right? Of Parkinson's. And if we can treat you with the following thing, if we can get you on an exercise regimen that may really slow down the course, right? Because a lot of the medicines that are in trials right now are to try to change the course of decline. If the Parkinson's is going down like this, we hope, you know, that a medicine will kind of slow that curve still going down probably, but hopefully slower. But if we could change that curve way up here and change it like this, that's many, many, many, many, many more years of better quality of life and function, rather than wait till we get here and then try to smooth out that curve from there. Right? So, the hope with these newer staging systems, incorporating DAT scans and other markers that are sort of coming up as the last couple of years have gone on, is to try to identify people at risk or people very early on and understand what's going on with them and let those lessons translate to people later in the disease as well. Great. It's a long-winded explanation.

Polly Dawkins:

Yeah. Well, it's helpful to set the baseline understanding of what we're being told and in doctor's offices and what we think we know. And so, now that we have a baseline understanding of, all right, staging, let's chat about this, the changes and that our care partners



are seeing and in their loved one and managing how do we manage change more specifically and based on what, you know, your experience. Tell me a bit about managing change.

Jori Fleisher:

I think thinking about sort of what's my loved one's normal range of change and what's outside their range, because those are really kind of important things. So, if we're sort of thinking on, you know, a day-to-day, week to week basis, right? Anyone is going to have good days and bad days kind of have good moments and bad moments, and those are what those looks like are going to change as time goes on and the disease goes on. But if you kind of stop for a moment and kind of, think about the last four weeks of your loved one, right? What's the best moment that they had? What's their best function where you were like, wow, I didn't even realize that, you know, you were able to do that, right? They really kind of blew your mind and what was the worst day and what did that look like, right?

And this is assuming that they haven't been sick, there hasn't been any huge stressors or big life changes, right? Kind of set those parameters of here's what normal kind of looks like. It could be anywhere from here to here, right? And so, as time goes on, what that range is going to look like will change, but never on a day-to-day basis. What do I mean by that? So, Parkinson's is a very slowly progressive disease. There is no one day when a big clump of dopamine cells is just going to be like, peace out; I'm done. We're off today. We're not coming back. Okay? There is no one day where, and I've heard this from people, you know, what if one day I wake up and I'm in a wheelchair, what if one day I wake up wake and I can't wake. There should never be a one day I wake up and moment in Parkinson's because it's slowly progressive.

The changes are happening on a microscopic level, right? And so, there's going to be fluctuation, there's going to be sort of, this is a better day, this is a better moment. But if we see a, I woke up one day and that should send big red flags, all the warning signals, all the things to say what else is going on. Because now a person's Parkinson's symptoms are their sort of warning that's the canary in the in the mind of something else is going on in the body. And whatever compensation was there for how they were doing has been lost. So, here's my terrible analogy, bear with me for a second. Imagine that like you are in New Orleans post Katrina, okay? And there's a lot of floodwaters, right? And sort of that is, that's Parkinson's, that's everybody. The situation is just, there's stuff going on.

Stuff is amiss, right? The National Guard is called in to build levies, kind of shore things up, clean stuff up a little bit, right? That's the compensation that your brain is doing on a daily basis. So, if that weren't there, it'd look a little bit messier, right? But most days the National Guard shows up, they do their job, they keep the sandbags in place, things are doing okay. However, if suddenly in the middle of Kansas there's a tornado and something's going on, some of the National Guard is going to be temporarily redeployed. if there's a urinary tract infection, if you get covid, if there's something else going on, a couple of nights of terrible sleep for some reason, right? The compensation, the National Guard goes away, the flood waters look worse.



Katrina didn't happen over again. We're still dealing with the same thing that we were before, but the compensation, the band aid, whatever, you know, we want to use for the analogy has temporarily gone away.

And now we see things looking a little bit worse. Okay? The National Guard will come back, right? They, it might not be able to clean up everything that happened before. So, sometimes if people have an infection, they have a hospitalization. You know, the question is, will I get back exactly to my baseline? It's hard to know. Sometimes we get almost all the way there. Sometimes we get all the way there. But it can take a while to sort of clean up from what we lost. So, if you know your loved ones range plus or minus, here's a good day, here's a bad day. This is what this looks like. And something happens and it's so it's far outside of there. Think infection, infection, infection, Constipation.

Was there a fall that I don't know about? Could they have hit their head? Are they in pain that they're not telling me? Could they be dehydrated? These are big common causes. And in terms of infections, people with Parkinson's are at a much higher risk of urinary tract infection, women, but also men. And it's one of these really sneaky things that the way it's going to show up is not, oh man, it burns when I pee and I have to go 10 times a day, it's going to show up through the Parkinson's. So, the tremor is so much worse than I've ever seen it, or my loved one has never had hallucinations. And suddenly they're hallucinating right from one day to the next. or the stiffness, you know, they can't even participate in physical therapy, or they can't do X, Y, Z, that even on a usual bad day, they could do. If you're seeing one of those kind of big step offs, it's not the Parkinson's, but it's something else showing up through there. We want to be really good detectives, figure out what that is, treat it, and then wait for the National Guard to come on back in and try and clean us up.

Polly Dawkins:

So, when you notice that as a care partner-

Jori Fleisher:

Yeah.

Polly Dawkins:

Do you call the movement disorder neurologist or your general practitioner when there's an issue that like this?

Jori Fleisher:

It's a great question. Some of it kind of depends on your general practitioner. Make sure that they know that your loved one has Parkinson's. You can always call the movement neurologist

first, but I am not up to date on antibiotics for urinary tract infections, right? So, if someone calls and they talk to me, they talk to one of our nurses and say, you know, hey, he was fine yesterday, but all of a sudden today, the first thing does not pass passcode, do not collect \$200, is our nurse says it could be a U T I or it could be constipation, or it could be dehydration. Call their primary. Tell them that you talked with us and we said, it's not the Parkinson's, it's something else showing up through the Parkinson's. Go get tested. So, my standard is always, always urinalysis, urine culture. If there's any chance of infection, if there's been, you know, someone around you with covid, which right now, October 2nd, 2023, we're in a rise again. So, assume that you've been around someone with covid you know, getting tested, figuring out what is this that's provoking these symptoms. Usually, the general practitioner is happy to help out and send off those labs, do those things once they know that, you know, the neurologist has been like, Parkinson's doesn't do this, something else is doing this, and just showing up through the Parkinson's.

Polly Dawkins:

That let's talk a little bit about the gradual changes and how care partners can help manage gradual changes.

Jori Fleisher:

Yeah. I think sometimes these can be really tricky to notice because if you're living with your loved one, or if you're seeing them, you know, on a day-to-day basis, some of those gradual things may not necessarily rise to the level of awareness. Sometimes it takes a friend or a family member who hasn't seen a loved one in a while to go, wait a minute, you know, where did, when did this come up? You know, it seems like they're struggling with this. So, number one to that, I say if you, and I've heard this from our care partners, they're like, I didn't even notice, you know, I didn't realize that they were struggling with this. That's because you are so close, right? if you're in it day to day, if you think if you've ever had kids, right? You may not notice when raising your kid, you know, okay, they just started doing this thing because you're seeing them all the time, right?

Sometimes it takes that distance and that perspective to notice some of those gradual changes. So, Parkinson's is unfortunately a progressive neurodegenerative disease. So, there will be change over time. Not everyone gets every symptom. So, sort of knowing about, you know, what the potentials are to be monitoring for, but not living in fear of this is all going to happen, right? No one gets all the things. And I think if you're seeing things, you know, asking your loved one, do you notice? You notice you're dragging that foot, you know, have you realized, is that happening? And again, it depends on the relationship, it depends on the person, how you ask that and what you say that you're noticing. Or, you know, maybe it's just me, but it looks like you're setting things, you know, on the counter and you're setting them on the edge more often.

Do you notice that? How's your vision? Have you noticed any changes? Sometimes they can be really subtle things, but if you're finding, you keep getting into an argument about something, they're doing something and you think they're supposed to be doing something else, it's probably not the person being stubborn. It might be a symptom of the Parkinson's. So, I bring up that like counter and the edge thing, because often there are subtle visual spatial changes in Parkinson's, and that can be something that sneaks in. Sometimes people are going through, you know, five different pairs of glasses and going, well, these don't work. These don't work. They're going back and forth to the eye doctor. And it may be an eye issue. There are some eye issues that can happen subtly and gradually with Parkinson's, but it can also be a visual spatial processing issue. So, the way that the brain is interpreting what's coming in and what this means is depth perception can be slightly off. And so, I had a couple that was really like getting into, you know, almost to like fist because she was convinced that he had a long-standing silent vendetta against their wedding China, because lately he was breaking it all, right? And I was like, huh. And it turned out, and I don't know if you can see this, but basically, you know, every time the person with Parkinson's would set something on the counter, where are we? Sorry, my depth perception's not great. They would set it right on the edge.

Polly Dawkins:

Yeah.

Jori Fleisher:

They thought that it was firmly on the table or on the counter, right? And so, how they felt about China, they thought that they were putting it front and center, and because of that subtle, gradual, not anyone-day change, their loved one was seeing this as a different symptom. So, sometimes just exploring that you know, sometimes folks have changes in like their blood pressure regulation, sometimes in their temperature regulation. So, if you and your loved one didn't use to fight over control of the air conditioning or thermostat, and now you're in this, you know, waging war against you turned it up. No, you turned it down, right? What's going on there? could that be right? Could that be a gradual change related to the Parkinson's? And so, keeping that list of things either that you talk through, hopefully with your loved one first, ask them what their experience is and then saying, okay, maybe this is something, right?

and bringing that to the next appointment can be really helpful. And that way, you know, the team can weigh in and say, you're right. We do see this change. Here's what we could do about it. right? Or you're right, this is a change. We don't have great treatments for it, but you're not, you're not imagining this. You are totally right. Here are some ways that other people strategize and live around this challenge or this change. So, the changes will come, but I would say being aware, being open about them. And there are going to be things that the person with Parkinson's experiences that people around them will never see, right? We can't, if we're not having a hallucination, we can't possibly know exactly what that looks like or feels like. And on

the flip side, there are going to be subtle changes that the person with Parkinson's may not have so much insight into that you as a caregiver may see directly.

Right? The brain accommodates and adjusts. So, a really good example of this is dyskinesia. So, dyskinesia is those abnormal, involuntary sorts of excessive movements that we can often see usually at the peak of someone taking their medications, right? And so, I have families that I know look at me and go, like, she needs to have her head examined because I'll walk into the room with their loved one with Parkinson's. The person with Parkinson's might be sitting there and having, you know, dyskinesia, they could be mild, could just be like a little bit of a head jiggle, could be a foot fidget, right? Or they can be tremendously, you know, big violent, obvious movements. And I'll ask all my usual questions and then I'll ask the person with Parkinson's, do you notice any dyskinesias? Do you ever have any abnormal wiggly jiggly movements? And I promise you this is not infrequent. There are people who are sitting there and doing this and going, no. And the loved one looks at me, and when the words come out of my mouth and say, do you ever have this? They're like, the reason I ask, obviously I see it is because people's brains accommodate. So, the person who's having dyskinesias, their brain is telling them that they're okay. The meds are usually working, which means they can move the way they want to. And so, any extra movement is kind of like that channel is turned down, right? They've muted that channel because their brain is in the, I can move space. The extra stuff doesn't register.

Polly Dawkins:

Right?

Jori Fleisher:

And so, you as the family member, you as a care partner might go, oh my God, they've got dyskinesia all the time. How does this not bother you? And the person with Parkinson's, like, oh really? When did you notice that? Sometime last week. So, you have a different perspective and insight on both gradual and sudden changes than they do, and both are valid and important.

Polly Dawkins:

Yeah. So, you've talked about sudden changes in park in Parkinson's. You've talked about gradual changes. We haven't really delved into sort of motor fluctuations as much on and off. Yeah. And then how can you tell the difference between what's on-off motor fluctuation, what's a cognitive fluctuation and then what's sudden change?

Jori Fleisher:

Totally. So, motor fluctuations, when we talk about that in Parkinson's, usually what that means is in someone who is on medication and typically on a dopamine related drug, usually levodopa

or carbidopa levodopa or Sinemet, we'll use those terms interchangeably. Okay? But levodopa is, once it gets to your brain, it's dopamine. It's what the person is missing. So, for all of us, our brains are normally making a slow, steady amount of dopamine all day long. The person with Parkinson's, their brain is making a slow, steady amount of dopamine all day long. It's just a much lower dose. early on, when people typically start medications, they will take the dose usually, you know, three times a day kind of spaced evenly during the hours that they're awake. And they may just take that first dose and they might notice that they feel better. They might not.

You might notice that they're moving better, you might not. But often it's kind of steady all day long as time goes on and their brain is making less and less dopamine, they are more dependent on the dopamine that we're giving them by pill form. And so, every time, if you think about if you've had a headache and you take Tylenol or Advil, you take the pill, it does not kick in immediately. And 10, 20, 30 minutes later, at some point you go, oh, you know what? My headache might be a little bit better. Right? And then if you don't, if something's still going on and you don't take another pill for a while, at some point that headache's going to come back. Okay? That is a headache fluctuation. So, people with Parkinson's are getting the same thing where the dopamine is covering up the symptoms, their tremor might go away.

If they've got a tremor, the meds kick in, the tremor is better, the slowness is better, the stiffness or dexterity issues are better. They can go on about their day, they're doing better. And eventually at some point, as they get to the end of a dose, as it is time to take that next dose, you start to see those motor symptoms that were better, you see them come back or get worse. So, we might have 15 minutes where tremor is really bad first thing in the morning, meds kick in and gradually the tremor is better. If there's a stressful conversation, something bad's going on, it can always pop out. But in general, we see sort of better, better, better, better, better, and wearing off, and now the symptoms are back.

And then we Take the next dose, and we go through the same kind of better, better, better, better, and wearing off and the symptoms come back. Those are motor fluctuations.

So those tend to be related to the timing of medication. Sometimes it can be hard sometimes if your loved one is missing doses, you might say, well, this doesn't seem to follow a clear pattern because they should be taking the meds they should be on right now, but they're not. Ask them if they accidentally forgot to take their meds. This was one of the test questions. But just because medicines in Parkinson's kick in and you can sort of notice them doing something for most people, more than say a cholesterol medicine, people are people, people are not meant to take medications. People forget to take their medications. They miss a dose, they take it late, they accidentally forget it at home when they go out and do something. So, medication adherence in Parkinson's is about as meh as it is in everything else. Okay? So, you might say, well, there's no clear pattern here, but ask your loved one if they're actually taking their meds when they're actually taking their meds.

Right. And see if you notice, wait a minute, you know what they're doing poorly, they're stiffer, they're shuffling their feet more at this time of day, actually that is 45 minutes or half an hour before they're supposed to take that next dose. Right? Those are motor fluctuations. We talked a little bit last week about cognitive fluctuations, which is sort of that idea of being in an airplane and you're sort of unpredictably crossing through the cloud layer outside of your control. Everything is kind of foggy, right? And so, cognitive fluctuations can happen separate from motor fluctuations. They have the same word. It's not the same thing. They don't happen together. That might make life easier. But so cognitive fluctuations are almost like someone is just bumping up against that dimmer switch. It's the person with Parkinson's, the person with Lewy body is suddenly for moments, for minutes, for hours, dazed less alert, kind of staring at you, not putting sentences together the way that they usually would, just kind of looking.

You can tell sometimes I have care partners all the time that say, I see the curtain come down. And similarly, they can almost see it lift. And it's not a seizure, it's not a stroke. It is something changing sort of in the firing, deep in the area of the brain that controls alertness. Right? And so, we don't know what triggered it. We don't have a good way to bring them out of it. You don't need to clap in front of their hands or try and shake them. You know, it's being in the plane and recognizing we don't have control over the turbulence,

Polly Dawkins:

Right?

Jori Fleisher:

So, if that's the moment where you're supposed to get up and get out of the house and go somewhere, or be on a call or do something, it's just not going to work right now. We're just going to be flexible. We're just going to wait until we come out of that. And if there's a particular time of day where the fluctuations seem to happen, make note of it. Bring it to the doc and might be, you know, maybe your loved one's getting poor sleep and if they're really sleepy, if they're hitting a patch of the day where they're just exhausted, right? There might be sort of a mix of, are they, are they dozing off to sleep? Is it a fluctuation? What is it? And we can kind of troubleshoot from there. And not everyone gets caught in a fluctuation, but as time goes on, and as people live longer with Parkinson's, they do become more common. So, those are sort of on the moment by moment, day by day motor fluctuations, cognitive fluctuations, and sort of them, you know, days, weeks are those sudden changes of, wait a minute, they were here, now we're here. What's going on?

Polly Dawkins:

And you, you mentioned before we hop into falls, which is our next topic here, really quickly when would you advise our care partners, our audience to raise a red flag on change? We



talked about sudden change, of course. Raise a red flag. Yeah. But any of these gradual changes to re-raise a red flag with their movement disorder? Neurologist?

Jori Fleisher:

I mean, I think if someone, you might, you might ask 10 different movement disorders, neurologists and get 12 different answers. So, my answer would be, you know, if there's something, and you are concerned, right? Especially if your loved one was not falling before and is now having falls or almost falls, right? If they would've fallen, if you didn't catch them, if they would've fallen, if that chair wasn't there or the wall wasn't there, and you're seeing that happening more and more, I would want to know if the person was not hallucinating before and now is hallucinating, I want to know if they're passing out, I want to know those are some of the big things. If there is any agitation or aggression. And I can't remember if we get into this later in the curriculum, but agitation, especially physical aggression, and sometimes in about a quarter of a case is sexual aggression from a person with Parkinson's or Lewy body towards a care partner is not uncommon. And so, it's not you if you take nothing else away from today, if that is happening, it's not you, it's not your loved one. It is the disease. And there are things that we can do, medication, non-medication, lots of different things. But if any of those things are happening, falls passing out, you know, we know that they're dropping blood pressure or they're winding up in the hospital or things like that are going on, that's when to call.

Polly Dawkins:

Well, that's a great segue into the next topic about falls and falls and fall prevention is so important in our community because we know it's a major cause of hospitalizations and a leading cause of death in Parkinson's. Can you talk about falls, why people fall? Why it's so, so negative of falls and yeah. What can we do about it as care partners?

Jori Fleisher:

Oh man, so much. So, number one, falls are incredibly common and there are lots of things that we can try to do to prevent, but you are not going to prevent every fall. So, that is not, it's not on you, it's not a failure on your part. It's not a failure on the part of the person with Parkinson's. Right? So, we talked about the stages, right? Stage three, balance, and posture are starting to get involved. So, Parkinson's affects that postural reflex, right? So, the ability that if you start to tip, if you start to lose your footing, that you can quickly regain that balance. And especially because for so many people with Parkinson's, posture is affected, which means instead of being upright, you're out here or maybe even further, which means the person's center of gravity, you know, could be way out ahead of them.

And so, they're almost always off balance in that situation, which means any slight change, the tiniest little change in like the grade of a sidewalk, right? Or there's, you know, something as a little bit uneven or a pair of shoes that are maybe worn down. You know, inconsistently could



be just enough to kind of tip them off balance, right? The other is, as time goes on, there's something called freezing of gait, which is where people's feet, it's almost like they freeze, they kind of get stuck in place almost like they're glued to the floor and the person can't kind of get going or move as seamlessly and smoothly as they would hope to. That happens more commonly as Parkinson's goes on, especially when someone is first standing up. So, we call that start hesitation where they kind of just need to kind of shift in place, get themselves going, and then they can move forward.

But the other common places where people freeze are going through thresholds of doorways, transitions. So, if there's a change in the flooring at a house, you know, in our clinic there's a spot where we go from carpet to wood, people freeze there all the time. If they're going from a big open space into a tight, narrow space, that can be a place where people freeze. And when people freeze, they're, you know, kind of stuck in place, they're even less able, if their balance is feeling slightly off, they're even less able to compensate because they can't quickly take a step back or quickly take a step forward or even, you know, necessarily reach out and grab something to stabilize themselves. So, balance in general, freezing of gait is a big contributor. sometimes that depth perception, the visual spatial things is, I have people that, you know, are veering and kind of bumping up into walls really frequently.

And the wall looks like it's over here, but actually it's over here. And so, if you're, if you just kind of bump the wrong way, we can all do that. Right. I'm, I'm certainly clumsy. If I bump it up against something I can usually right myself because my balance reflexes are intact. Right. But if that's not the case, the visual spatial change can be enough to set you off balance and set you up for a fall. And the challenge is when people fall with Parkinson's. So, if you don't have Parkinson's, when you fall, you try, usually you reach out to catch yourself whichever way you fall, you try to fall in some way that your kind of, it's a reflex. We don't think about it. We brace ourselves and try not to hit, you know, the really important stuff.

Right. But those reflexes diminish in people with Parkinson's. So, people will fall forward and will hit their noses on the ground, not their hands first. They'll hit their faces. And so, that's a huge risk of head trauma, of having a bleed inside the brain, especially if someone is on a blood thinner. Yeah. Your loved one is on a blood thinner and falls, especially if they hit their head. I don't care if they've got a scratch, if they hit their head, if there's a bump, if there's something that is usually you go straight to the ER because you can hide a bleed internally without necessarily seeing something from the outside. So, we take that really seriously. The other thing is if people fall and they fall backwards, for example, or they fall to the side, people with Parkinson's are much more likely to break a hip. And that can be a huge injury for people that sets them back and really takes away mobility. And some of that reason is also that is mobility is changing. If people aren't, you know, really exercising, if they're not keeping up their muscle mass, sometimes folks with Parkinson's will lose weight unintentionally. And everyone is like, ah, great. Alright. You know, this pair of pants fits. No, it's not the good weight loss that the rest of us want. It's muscle mass. So, people can still, you know, the pants are tight, but their arms

look scrawny Or You're seeing that their calves look kind of scrawny. What that means is the muscles that are there to help, if they start to lose balance, if they start to tip the muscles to try to catch themselves and the cushion between the ground and those bones is less, and so, they're less able to catch themselves when they start to fall, and they're more likely to break something because there's less of that muscle cushion there.

Polly Dawkins:

Boy, that leads us into the next question about exercise and what, what can, like, what can we do to support our friends with Parkinson's, our loved ones with Parkinson's to support that they do better and prevent falls from an exercise perspective? What are recommendations you have?

Jori Fleisher:

So, I mean, the simple cliché is if you want to keep moving, keep moving. We are not going to prevent falls by not moving. We're going to, if someone says, you know, I'm afraid of falling and fear of falling is huge. Fear Of falling is a really big picture. If you have ever walked across an icy parking lot in the middle of winter, wherever you are, if there's black ice, you can't see it. You don't know. And you do that teeny tiny little step, right? People with Parkinson's often have such a fear of falling that is how they are walking.

Just because of that. Right. And your balance when you do that is not great. Their balance is even worse. Right? And so, sometimes that fear of falling leads people to not move. We need to move past that. The only way to get past it is to move. So, if your loved one does nothing, they are sedentary, they are stuck at home, they're not doing anything. Start with physical therapy. A physical therapist, especially someone who's trained in Parkinson's will be able to start from zero and help them move the needle forward, right? Can find some kind of exercise regimen that they can do. It may not be the world's most perfect Parkinson's exercise regimen, but something is always better than nothing. And the more we get people moving, the better. If your loved one does already move, there's, I mean, there's so much evidence that exercise is crucial. It is the secret,

Polly Dawkins:

Right,

Jori Fleisher:

If anything, it is the one thing so far that looks like it might change that trajectory of how quickly Parkinson's progresses and it's in your control, right? The medicines so far are covering up symptoms. They're not yet slowing down progression, but exercise might. I often get the like, well Joy, what's the best exercise? The best one is the one your loved one will do.



Polly Dawkins:

okay?

Jori Fleisher:

If they bike, bike, if they run fantastic, if they swim, if they tap dance, I don't care what it is. There's wonderful evidence. So, there's a great talk just at our big international movement disorders conference this past couple a month ago. All exercise seems to be good exercise and all exercise may not be created equal. So, there's really good evidence around dance for Parkinson's, different kinds of dance, but it's big movements. It's movements that are getting you moving, getting your heart rate up, are pushing the needle on balance a little bit, pushing you out of your comfort zone, but in a safe way. And getting you to move music. And auditory queuing can really help people who get stuck. So, it kind of makes sense that dance has music involved, so it can kind of get you out of a freeze if you need to. So, there's great evidence behind that, but there's also great evidence behind biking, especially biking that pushes yourself. So, shout out to Davis Finney and the Davis Spinney Foundation for, you know, doing so much work around cycling. It is tremendous and it's building resistance, and it's building aerobic capacity. So, that's huge. Swimming

Polly Dawkins:

Good for the heart, and

Jori Fleisher:

Yes, it's good for everything, right? And exercise from an endorphins perspective and just making people's mood feel better is huge. Ah, so huge. So, huge. So, then there was a study a while back that looked at like, well, how much, how much exercise am I aiming for? And so, there is actually like a prescription and the goal is at least 150 minutes per week. Not all at once can be divided up, we think however you want, 30 minutes, five times a day. But 150 minutes a week of aerobic movement, something that challenges the person with Parkinson's, that or above seems to make a big difference.

Right. If your loved one is doing nothing, don't push them to do 150 minutes this week. It's going to backfire. Right. They're going to get sore, and then they're not going to want to move again. Right. But knowing that's our goal to work towards, how can we find moments of movement and activities that we love to sneak in there and add up to that sum. Yeah.

Polly Dawkins:

I recall speaking with boss Bloom, who's a movement disorder neurologist in the Netherlands, and he talks about little exercise snacks.



Jori Fleisher:

Yes. So, even

Polly Dawkins:

If you can get a five-minute dose as a part of your, it's a little snack. Even if between things between, you know, advertisements on television, a five-minute exercise snack is better than continuing to sit.

Jori Fleisher:

It all counts. And for some people, they're really motivated by, you know, being able to like, check it off. Right. So, can you, you know, maybe you have like something that you're just going to color in. Right. And every day it's got, you know, up to 30 minutes. Right. And you do a few minutes here and a few minutes there. Right. And you can sort of check that off or put that into an app. Fantastic. But whatever it is, I love the, if you're going to sit and watch tv, that's okay. Everyone does. Right. But there are enough commercial breaks. Use the commercial breaks as movement breaks. Just go do laps around the house. Go sit there and grab some hand weights, grab some cans of tomatoes. Right. Whatever you got. Use it. Do some, do some movements—and strength training. So, like actual, you know, using weights or body weight resistance has great evidence in Parkinson's.

I would say the one mistake that I see people do is everyone, everyone likes to do bicep curls. They like to do this; they like to do their chest presses. This is all good. However, Parkinson's in particular, it's not really affecting, it's not weakening those flexion muscles. we have problems with extension, with big posture, back muscles, core strength. So, Cool. Do the biceps. That's fine. It makes you feel good. Right. But think about core strength, think about back strength think about triceps, sort of all those, the muscles that we don't use as much, and we don't like to work as much. Maybe we need to work those even more.

Polly Dawkins:

What are, we're sort of mixing exercise and falls here, which is great because they're so related. Right. But tell us about some things that as, as care partners we can do well, what are things that can actually increase the likelihood of falls and that we should stop doing, or our people with Parkinson's should stop doing?

Jori Fleisher:

Yeah. So, a couple different things. So, one of the places that people fall most frequently is at home in tight spaces, particularly the bathroom or in the kitchen. So, taking note of if your loved one is falling or almost falling were.

Where are they when these are happening or they're almost happening and what exactly, like, what movement are they doing? So, a lot of times, so freezing of gait, for example, is triggered in tight spaces. So, we can't all just, you know, blast out walls in our bathroom and make them bigger. But if your loved ones struggles and they're getting their toes, you know, tied in knots in the bathroom, sometimes having like bright neon colored non-skid tape, that's essentially a like step here and now step here. Visual cues that can help someone where if you know their feet are getting stuck. Okay. Nope. Step on this one. Step on this one. If you actually, you know, look on Amazon, things like that. Non-Skid bath stickers. They may not be the prettiest, but they're fun. Those can be really good. Grab bars professionally installed, grab bars.

Do not just use suction cups for grab bars. Your loved one will fall and take it down with them and pull-out tiles. Okay. but grab bars in bathrooms or other spaces where they might tend to fall. Any rug that is not tacked down and has a non-skid bottom is a huge fall risk. So, when we were doing home visits Serena, our nurse who you'll, you'll get to meet in one of the other sessions. Serena would walk through the home, and she would see that, you know, people have these beautiful throw rugs, right? These beautiful runners and things like that. And there's almost always one corner or some fringe or a lip that's kind of turned the wrong way. It's catching up. If people are using a walker, the walkers will often get stuck and caught, and the person with Parkinson's will fall over there. Or people shuffle their feet with Parkinson's. They're not picking up their feet as they take steps. They're just kind of shuffling forward. And so, if you shuffle into something where there's a lip like that and the rug could kind of pick up underneath you, that is a big fall risk. So, rugs, if we can't get rid of them, which would be choice number one, right? Is get rid of it.

You're better off without it. The amount that it might cushion a fall, if your loved one falls is outweighed by the, it's causing the fall. Get rid of it, and they won't fall in the first place. Right. So, if it is a dear family heirloom, and you cannot imagine getting rid of it, and no one else in the family wants to take it, cool. Now it's a tapestry. Put it on the wall. If you don't love it enough to put it on the wall, maybe that's a sign that you could get rid of it and someone else could make good use of it. Right. So, think about things that move under your loved one's feet. This could also be like kitchen mats. Or sometimes that the other time that we see people falling and so, carrying things, multitasking carrying things and trying to set something on the counter.

So even though we don't think about that as multitasking, walking, and carrying a dish for someone with Parkinson's, some part of their brain, some of the National Guard is now paying attention to keeping that plate or that cup steady. And there's less attention to be paid to making sure that they're stepping in a safe way and maintaining their balance. So, if we can take away the carrying of things back and forth, forth or throw it in a bag over the shoulder. Right? Never, never, never should people with Parkinson's be carrying laundry up or down stairs. You tell folks all the time, if it's dirty laundry, it doesn't matter because it's not folded. It

doesn't matter. Throw it down the stairs or put it in a bag, throw it up the stairs, wherever it needs to go. It's dirty laundry. Right? It doesn't matter if you throw it.

If it's, you know, if you're moving it from place to place, you can put it into a bag, sling that over a shoulder, if the person absolutely must carry it, but not in their hands, hands should be free to hold onto a banister if they're going up and down stairs led onto a railing. And in the kitchen. The other thing that I see is if you have a refrigerator where this is the case for many of us is like, you go to start tugging on the refrigerator and you know how there's that moment of kind of tension where it doesn't quite give yet, and then it snaps open. Anything that does that, any refrigerator, any washers, dryers, anything that has that moment and then pull. If you think about someone who has a hard time catching their balance when they're thrown off balance for a second, that is a natural setup.

So, I've had people who, you know, not only fall when opening the fridge, but fall and take a walk or over with them. I've had people fall and they almost pull the fridge. And so, you know, if your loved one is unsteady on their feet, thinking about those things, and let me get that for you. Or let's, you know, try to set the things out ahead of time that they might need, or put that down. If you're going to go here, stand to the side of the fridge and open so that you're not going to be knocked off balance if you're pulling straight out this way.

Polly Dawkins:

That's a great strategy. What about the stress that the fear of falling puts on the care partner? What, what is huge?

Jori Fleisher:

I feel like our folks are constantly walking around, you know, wanting to almost put their loved ones in bubble wrap, right. Is just, you know, it's on me to prevent every single fall, right? we just can't. Right? You can control the things that you can, you can notice the patterns or the triggers. And sometimes there are none, right? And that's okay. Also is to say they're falling once a week and they don't know why, or they're falling and I'm not there. They're falling when they're out doing this or when they're working in the garage or when they're out in the garden, right? But that's at least an entry point for the healthcare team to try to figure out what's going on. And if we can't, physical therapy is a wonderful place to start. So, our physical therapists, again, especially if they've been trained in Parkinson's, we'll work with someone on how do we have that better posture so that we're not stooped forward and prone to falling? How do we work on things? How do we get stronger? How do we work those muscles to help sort of with balance and with, with giving you a little bit of wiggle room, right? How do we take bigger steps instead of small steps, which is sort of the inclination. You actually want to take these big, large amplitude steps. You want to swing your arms really big. It actually keeps you steadier. So,

Polly Dawkins:



We've delved into the topic of exercise, but it's a natural combination exercise and falls. And we're not going to really dive deeply into exercise and the benefits of exercise here today because it's so well researched. We know this. We keep being told this, that exercise and Parkinson's go well together. And as Mel pointed out in the chat, good for person with or the care partner too.

Jori Fleisher:

Yes. Yes.

Polly Dawkins:

Exercise. I noticed in the chat, even though I'm not supposed to be watching it that somebody alluded, alluded to the role of the care partner, the role of all of you on this webinar that you play when it comes to exercising for your person with Parkinson's, and especially as, as it Parkinson's advances a bit, and the nagging that might feel that it gets accompanied with, with that. Can you talk a little bit about?

Jori Fleisher:

Yeah, I think it's so common. I mean, you are in the position of being the cheerleader and the coach and the teammate, you know, doing the exercises with the person sometimes is the only way. And it's not like you have nothing else to do. Right? and so, if your loved one will let you in that way, and that is feasible for you to do the exercise with them, or if they're going to a class and there's a, you know, care partner class going on at the same time as a person with Parkinson's class, fantastic. You're setting a great example, right? And having, having an accountability partner or buddy is something that's well established in exercise for anyone, right? I'm much more likely to work out if I know that someone is meeting me at the class or they're going to be on the bike at the same time, right? And so, sometimes that works really well for care partners with their loved ones.

I also have many people who I take care of where the care partner is constantly trying to get the loved one exercising. They know that it's the thing to do. And the person with Parkinson's just cannot hear it from them. Will not, cannot, won't do it not happening. Right? That's when it's not you. Right? But who else could you recruit? Is there someone in your network? Sometimes people will say, no, no, no, no, no to everything suggested by the person closest to them, right? If you have kids, you probably know this to be true too. right? They won't eat that thing, right? They will not eat a vegetable for you, but oh my gosh, they had the best broccoli at auntie so-and-so's house, right? And so, you know, this is not to diminish this. And it's not a child, you know, reference, but it may be easier for the person with Parkinson's to be motivated and not instinctually say no to someone who is not you as their primary care partner.



So, is there a friend, a neighbor, another family member? Is there someone, even if they're doing like a virtual class, can someone get on Zoom or FaceTime with them and do that at the same time? And that's kind of there, you know, their date and then you as a care partner have that time of respite, right? Sometimes what I've seen really successfully is in folks who, for whatever reason, you know, have brought in a paid caregiver or a paid, you know, home health aide of a sort or companion, the person with Parkinson's might be far more willing to go for a walk, get on the bike, do the class, do the yoga with the companion than with the person, you know, who's their primary care partner. So, if that is a reason to bring someone in, I've had families where, you know, because of the Medicare and other legislation in the us we all wish that people with Parkinson's were just eligible for physical therapy all the time.

Would that be helpful to have continuous access to physical therapy, the entire duration of the disease? Absolutely. Will Medicare let you do that? No. So, I have some folks where they've come to the end of their physical therapy chunk of sessions, and then they're like, that was great. I want to keep this up. How do we do that? And maybe the person with Parkinson's is going to be able to do that on their own. Maybe you as a care partner can cheer them on and coach them on and they'll listen to you. Maybe you can find someone else to practice those exercises and look online. There's lots of great content online. I've even had families who go so far as to reach out to physical therapy graduate schools, training physical therapy students who are not certified. Right? But it's basically like if you had placed a classified ad saying like, hey, do you have free time?

We're offering a part-time job to come and hang out with my loved one. And like with them, do yoga with them, dance with them, whatever it is. If you can find a physical therapy student, they're student. So, they're probably low on cash. And so, they may be, you know, thrilled to learn something, learn about Parkinson's, incorporate what they're learning in the classroom with real life experience and a person that they can connect with. You might even make them want to go into Parkinson's specialty care just by that virtue of that relationship, right? So, it's an out-of-pocket cost and it's not feasible for everyone. There's not a physical therapy school in everyone's backyard. But I've had people do that really successfully. I've also had folks reach out to, you know, local parent groups on Facebook and other things and say like, do you have a teenager who's looking for a part-time job? Will they come and do yoga, dance, take my loved one to such and such a thing, go for a walk around the block. Right? So, it's kind of thinking creatively about like, where could I find someone else who my loved one will respond to better in this situation? They get the benefit, the person who's helping them, you know, gets benefits in different ways, and you as a care partner can rest assured, they're doing everything they're supposed to be doing. And you don't have to do it all. You can't.

Polly Dawkins:



Yeah. Well, we do know that exercise is so important for care partners. Yes. But it seems as though what you're saying is not always doing it together might not be the best strategy for the relationship, for the tension that might exist or the level of exercise that you may need to get.

What? Tell us a little bit about what you found out in the field meeting with care partners and families about the differences between care partners who exercised and those who didn't.

Jori Fleisher:

Oh, absolutely. I mean, people who exercise it is, it's a natural stress reliever. It's a natural coping mechanism, right? And I think people who exercise seem to have less strain.

And you might say, well, sure, if they've got the time to be able to exercise, then, you know, that's right. Scientifically, that's biased, right? You're confounded. Because if they've got the free time to exercise and they're not being pulled in so many directions, maybe, but it may also be that they've prioritized exercise because that helps their own health. And they know that if their health is better, they can be a better care partner to their loved one. So, is it worth finding someone else, you know, who can be there with your loved one so that you can go to your exercise class, unroll your yoga mat, do meditation, you know, get on the bike, go for a walk, whatever that is, the research says yes. That it's better for you in the long term, both physically and emotionally, and it's better for your person with Parkinson's in the long term too.

So, we just share this anecdote because it was one of the most inspiring things: we actually studied karate for people with Parkinson's a couple of years ago. And spoiler alert it worked. It was really exciting and a lot of fun, and we're still, you know, working on publishing some of those papers. But it was a regular adult karate class that anyone could take. And we trained the instructors about Parkinson's so they could kind of adjust their teaching style a little bit, but it was still the same content. And we had folks who signed up for this, and for many of them, their care partners went with them. And the care partners hung out, sat, you know, on the, on the bench, on the bleachers and watched for 10 weeks. And the first study and then six months actually in the second study, watched as their loved one went through learning the moves, doing the kata, the different patterns of things.

And, you know, they were sitting, and they were the cheer squad, right? And making sure that their loved ones got there and that they, you know, had everything that they needed. But what was so great was there were several of the care partners who once the formal study had concluded, the instructors kind of looked and they knew, they recognized their faces. They were there, you know, every class, they looked at them and said, okay, you're up. You've been watching this time. And so, we had a couple where the woman was the person with Parkinson's and her husband was watching her, you know, for, from this beginning study and taking photos and documenting, and it was just, it was fantastic. The amount of support, you know, that we could see every photo of karate class, we saw him in the background, you know, and just beaming, right?

But then it was, all right, it's your turn now. Right? And so, he joined the karate class and she's ahead of him in terms of belt testing. you know, she went ahead and got, you know, this and he's kind of falling behind. But they've been able to do that together, right? That didn't work for everyone. And that wasn't something that we even intended. But if that's, if there's something that you enjoy, if you played tennis before, you know, and maybe tennis is more difficult, but you could do pickleball together, right? Or you could go to the court and maybe your loved one is in a slightly different league. You know, when you're playing a more vigorous game, great. But if it's something that you enjoy and you can talk about together and you can look forward together, right? And you both know the benefits that you each receive from that; I think that's really powerful.

Polly Dawkins:

Well, we know the benefits that exercise has on our care partners, on our, both the ones with Parkinson's. We also know that exercise has benefits for symptom management and for so many different symptoms of Parkinson's. And one of the symptoms we want to talk about today is constipation.

Jori Fleisher:

Yes.

Polly Dawkins:

Another big topic. And so, let's segue into constipation. because We're already getting on with our time here, and you and I could talk all day, but our audience probably has things to do. But we know constipation is so common in our in our population of people with Parkinson's. Doesn't make it any less frustrating or difficult knowing how common it is. But in the pre-session materials, we shared a bunch of information on constipation and gut. So, perhaps in a really short way, you could tell us why is constipation so prevalent or so common in Parkinson's story?

Jori Fleisher:

So, we know that Parkinson's, actually, it may be starting in the gut, we're finding some of the earliest signs of Parkinson's in cells that are in the gut rather than in the brain. And so, just the same way that, you know, if your loved one's movements have slowed down, think about their gut, right? The gut is supposed to just kind of move things through. If you imagine sort of just kind of slowly moving solids along the gut slows down, which means that you're not processing food is not moving through your gut as quickly. And your gut is like, well, I got something to do. I'm supposed to absorb something if there's material here, supposed to get something out of this. And if things are moving really slowly, all the nutrients have been absorbed, all the calories

have been absorbed, and your gut is sitting there and going, all right, I guess I'm supposed to take water out of this.

And so, stools become very slow moving and very hard and can basically become this boulder that eventually goes from being 10 miles an hour to five miles an hour to stuck. And that can become really, really difficult situation where people with Parkinson's are, you know, spending a lot of time straining, trying to go to the bathroom, not able to move their bowels you know, really, really struggling. And related to that is there are muscles that need to relax and muscles that need to squeeze to have a bowel movement. And the messages are getting mixed in Parkinson's. So, even if stools were softer, sometimes people are spending tons of time pushing and straining against kind of a closed door. So, lots of different things that we can do to help kind of both of those things. Both the slow movement or slow transit issue and sort of that pelvic floor muscle mismatch.

Polly Dawkins:

So, let's talk about those strategies as, as care partners here. What can we do to help with constipation?

Jori Fleisher:

So, prevention is number one. Okay. So, if we can, we want to prevent it. We want to recognize that your person with Parkinson's is prone to constipation. By which I mean if they're not having a bowel movement at least every other day, that's kind of the goal. Then they're probably somewhere in the constipated range. So, hydration and movement and fiber, hydration, movement, fiber. Ideally the fiber is coming from food, not a mix in kind of powder, Metamucil, meta fiber kind of thing. Those can actually make constipation worse sometimes in people with pd. So, as much hydration as possible will help. because Like I said, the gut is kind of sucking all the water out of things. We want to put the water back in. And the more the person with Parkinson's moves, that actually helps stimulate the gut to pick up its own pace and to move things along. So, there's kind of, at baseline, we want to be moving, we want to be hydrating.

If someone is really struggling with constipation, often it takes kind of a stepwise approach of like, let's try this thing. And so, there are a lot of different dietary things that we can try. So, people tend to be really interested in like probiotics. Yes, you could take a pill, but probiotics are good bacteria that are found in lots of foods. So, anything fermented or funky. So, yogurts do not have to be a specific brand. Pretty much all yogurt contains lots of live active cultures. If it says that you're good, pick the one that you like. Right? Anything fermented, like kimchi, sauerkraut, Keefer kombucha, all the Ks, I guess. All of those things are fermented, which means the good bacteria are in there doing their thing. Those we think can help. And then fruit, beans, vegetables, all of those are bringing a ton of fiber in, but also a lot of water.

So, the combination of fiber and hydration is really, really good. So, there are a lot of recipes out there that people will put together to try to help with constipation. There's something called the Rancho Recipe, which is quite famous. It's been around for a long time. I did not create this recipe. I'm a better cook than this. But what it is you go to the store and you're going to mix equal parts, prune, juice, applesauce and bran, any kind of brand, oat wheat, rice, whatever's on sale. You just pick it up. Bob's Red Mill or the aisle in the grocery store where they've got all of the various, you know, alternative wheats and flours. Go there, pick a brand you're basically mixing equal parts of those three things. Prune, juice, applesauce, brand, stir it together. It usually keeps for about a week in the fridge, in a Tupperware container, two tablespoons every morning.

And you can do that plain. Some people put it in yogurt, they put it in oatmeal. That is sort of a good high-density source of fiber. Is it the tastiest thing your loved one will ever put in their mouth? It is not. Some people just do not like it. But there are some other recipes out there. There's something called the fruit paste. There are a lot of different things, non-medication, that can be used to kind of try to stimulate better movement. And if we need to, there are plenty of medications that we can also use. So, things like Coase and Sinemet and Docusate and Dulcolax; those are a lot of the ones that are out there. The challenge with some of those laxatives and some of those stool softeners is in people with Parkinson's. Their gut gets used to it over time.

It might work for a period of time and then it stops working. The one that tends to work long-term and does really well is something called polyethylene and glycol, which is the generic name. Sometimes MiraLAX is the brand name. Stores carry their own store brand. Usually, it's usually a jug of a powder. And so, people can use that often stirred into some kind of liquid. And that can really help. It's bringing water into the gut to help.

Polly Dawkins:

Got it. Got it. So, in summary, I'm hearing care partners can help by monitoring diet, providing good food, ensuring exercise happens. Yeah. Any other things I neglected.

Jori Fleisher:

I think just recognizing, I mean, it may not be part of your normal relationship to talk about the frequency and consistency of your loved one's bowel movements. For most people, that's just not part of the breakfast conversation. Right. But rec, I don't know. But recognizing, you know, this is a big part of Parkinson's, and it can be a huge quality of life factor if someone is spending hours in the bathroom or planning outings around whether or not they've gone that day or whether they're going to have to go back to the bathroom. So, coming at it from a, I want to talk with you about this. I noticed that you might be spending a lot of time in the bathroom.

Do you think this is something that we could work on? I've heard that this is actually a very treatable thing that can be really powerful. So, that can be sort of the entree and the other just flip other quick thing that I'll say is that pelvic floor muscle issue where they're not kind of in sync with each other. The very simple fix for that is they found that people who sat on the toilet with their knees elevated. So, sort of mourn a squatting position, but not, don't actually squat, don't hover. That's not safe bounce wise. But if you can put a step stool underneath the person with Parkinson's, feet raising their feet so that they're just, their knees are a little bit more crunched up towards their chest, that can actually help those muscles kind of get back in alignment a little bit.

And minimize some of the straining and the risk of hemorrhoids. We want to be really attuned to the constipation because as unappetizing and unsexy as this is, people can wind up in the hospital because of severe constipation and it is not pretty, and it can be life-threatening. So, if things don't move, the gut gets really sick. And so, it is something to stay on top of, to be mindful of, to let your loved one know this is, this is part of it's not you. And we're going to try and do all of these things.

Polly Dawkins:

Yeah. And medications don't work as well when you're constipated. Correct.

Jori Fleisher:

A hundred percent. Yep. You can't absorb your medicines as well. So, sometimes we'll go around, you know, changing meds because someone hasn't told us that actually. Like they're going to the bathroom once every four days. Right. And if we could fix the constipation, the same medicine regimen could be much more powerful and work better. Right. And so, yeah, if nothing else, water, hydration, it doesn't have to be plain water. Anything that's not caffeinated counts. And the only issue with caffeine is caffeine's a little bit. Dehydrating, it has a diuretic effect. So, if your loved one wants to drink something that's got caffeine in it, fine, just balance it out with an equal or slightly larger amount of something unci caffeinated. So, and is.

Polly Dawkins:

There a, is there a rule of thumb about how much liquid to drink.

Jori Fleisher:

Or not really? I mean, there's not a great rule of thumb. Our dietician, I work really closely with the dietician, and she tries to get people close to those 64 ounces of fluids. Sometimes that could come in the form of, you know, a pair or watermelon, right? Is those are bringing a ton of fluid. So, soups, right? If you're having like a broth-based soup that counts as fluid. So, it doesn't just have to be plain water. And if your loved one is okay with water, finding the right water

bottle that someone actually will slip out of consistently makes a big difference. Right. Everyone has a different one. Okay. They're all different. Great. And yes, if it's brightly colored, so you can't lose it even better. I have some folks where they've literally taken a sharpie or permanent marker and they've marked times of day on their water bottle and their loved one knows, okay, we start with a full bottle first thing in the morning by, you know, 9:00 AM we need to have, you know, drank down to this level.

and by this time, we need to drink down to this level. Just that visual cue can be really helpful. Flavor drops, so like Dasani meal, crystal light, Kool-Aid, anything that makes the water more interesting. A lot of people just aren't plain water drinkers. You can judge it up and make it more exciting. Throw in some lemon water, you'll feel like you're at a spot. Right? It's totally dependent on taste. Recognizing taste is different, sense of smell is different. But whatever it is that can motivate your loved one to actually get them to stay hydrated is worth the effort.

Polly Dawkins:

Before we switch to the next topic, are there any medications, Parkinson's medications or other medications that make constipation worse that we should be on the lookout for?

Jori Fleisher:

It's a great idea. So, the Parkinson's medications don't tend to make them worse. But there are some things that people could be on. So, there's a class of medicines called anticholinergic. These are medicines like Oxybutynin, which is a bladder medicine. So, medicines that we use to try to you know, get things to kind of stop moving ways that they shouldn't that can sometimes be more constipating. And so, we want to be careful about that. There are meds that are better and meds that are worse. In terms of that, there are also anticholinergic medicines in a lot of over-the-counter preparations of things. So, any PM medicine, not the actual whatever came first before pm, but the PM or nighttime, that is usually a medicine that not only can worsen memory and thinking and cause confusion in people with Parkinson's, it can also lead to constipation, side effects pain medicines such as narcotics or opiates, so not Tylenol, Advil, those kind of pain medicines, not that, but things like morphine, oxycodone, things like that someone might receive, you know, for severe pain or injury or surgery.

Not to say people with Parkinson's cannot get those in situations where we need them. We don't want someone suffering and in pain. But if your loved one for some reason is on a medicine like that, know that whatever they were doing for constipation beforehand, you are probably going to need to double it at least while they're on that pain medicine, because those cause constipation in people without Parkinson's—got it. The other last tricky thing that I'll say is sometimes people will say, okay, I'm going to bite the bullet. I'm going to start something for the constipation, and then they'll call me a day or two after, particularly this happens with MiraLAX or some of those, bring the ones that bring water into the gut and they'll go, eh, she

was constipated yesterday. Now we've got diarrhea. We're just trying to find a middle ground. Right.

This is really tricky. So, this is something called overflow diarrhea. I know you all signed up and really wanted to talk about diarrhea today. I did not know going into neurology I would spend so much of my day talking about poop, but here we are. So, what happens, I told you that people get this boulder of rock-hard stool that's kind of blocking the exit. When you bring in MiraLAX or medicine that kind of softens things up or brings water in newer, fresher stool gets that first so it gets softer and sometimes it can liquefy and scoot out around the boulder, which shows up as diarrhea. So, people will have that and go, ah, and they'll stop whatever medicine or treatment they just started, the boulder is still there. Right. So, it feels super counterintuitive, but we actually want that diarrhea. It means everything else is getting out of the way so that the MiraLAX can get to that boulder and make dissolve it, break it up, get it out, and then we can sort of be at a nice, closer to normal baseline. So, if you're going to start something like that, maybe start on a weekend. Don't start it on a day where you have a lot of things planned. Anticipate that there could be that diarrhea and know that's not a reason to stop. It's actually a reason to continue. It's a sign of success.

Polly Dawkins:

That's very helpful, thank you. Anything else about constipation before we move into dizziness? Lightheadedness?

Jori Fleisher:

No, it's a lot for everyone for the day. Poops. I mean, I have young kids at home, and you know, take care of people with Parkinson's. So, my whole day, it's my whole day.

Polly Dawkins:

Well let's talk about the last topic we have for today and then see if we have some time for questions. So, neurogenic orthostatic hypotension, nOH is a common symptom of Parkinson's and Parkinsonism, atypical Parkinson's. Can you tell us what is this big word Yeah. And why it happens. And then thinking about the lens of our care partners, why is this important for our care partners to know about this?

Jori Fleisher:

So, if we break it down, so hypotension, the last word means low blood pressure. Orthostatic has to do with posture whether you're upright or not. And neurogenic means it's coming from a neurologic cause. So, neurogenic orthostatic hypotension means there is a neurologic cause for why when someone changes position against gravity, their blood pressure drops. And so, just like I said, that Parkinson's gets involved in the cells in a person's gut early on, Parkinson's gets

involved in nerve cells outside of the brain early on. And so, there is this autonomic nervous system, which is sort of everything that we take for granted. Everything that's automatic, which includes blood pressure control, temperature control gut mobility, right? And so, all of us should have a reflex in place where if we've been lying flat in bed all night long, the blood naturally kind of pools in your legs and in your gut.

If you've been sitting for a long time listening to someone talk at you for two hours, right? The blood is pooling in your legs and in your gut if it's hot where you are, if you're relatively dehydrated, if you stand up really quickly, I think all of us have gotten that sensation at times of like woo. Right? Where you feel a little lightheaded, you feel a little unsteady. Sometimes you get kind of the Twinkies in your vision stuff might gray out for a second or you just feel not right. That is a momentary gap in the blood pressure that your brain needs and the blood pressure that your brain is getting.

That is what people feel with Parkinson's. And the problem is that for the rest of us who don't have Parkinson's, our body is able to catch up that autonomic nervous system, even if it's a sudden change is able to tell the blood vessels in your legs and in your gut clamp down, push all of that blood flow back up to the heart where it can be shunted and pushed back up to the brain, right? Because your brain is now fighting harder against gravity when you change position. But that reflex of getting all that blood flow back up to the heart and to the brain doesn't work as well in people with Parkinson's and some of the atypical parkinsonism, it can be even more pronounced and can be sort of one of the first signs. And so, some people may just notice with Parkinson's who have this neurogenic orthostatic hypotension or nOH, they may notice that they go from sitting to standing, and they're like, oh, okay, I just have to take a minute.

They may not need to sit back down. They may not even like stop them for more than a second, but they just kind of notice, like, oh, I just don't feel quite right as time goes on. That can be more significant. And you know, if it's untreated, which implies that yes, we can treat this, there are things we can do if we recognize it, right? Is, you know, people can pass out because of this. So, that feeling, if you've ever been, you know, out gardening and it's hot outside, and you haven't hydrated, and you stand up super quickly, right? And you get the dizzy, you get the stars. If you had just stood up there and it was bad enough and you didn't listen to that warning sign, right? Those signs that you're feeling, that's your brain saying like, you got a two second warning. Either you put your brain flatter right closer to your heart, not having to fight against gravity so much, or your brain will do it for you, meaning it will make you pass out. Which usually makes people fall so that they are flat, and their brain is having an easier time against gravity. And so, that feeling people get telling people like, no, listen, when you feel that way and everyone describes it differently when you get that feeling, sit back down, hydrate, if possible, lay flat feet up.

Polly Dawkins:



what other strategies can we help our loved ones with Parkinson's get back down, hydrate, whatever.

Jori Fleisher:

Yeah. In the moment. So, in the moment when it's happening sometimes, like making fists moving the feet, just trying to get the blood flow moving so the person feels better and then slowly changing positions after that coming sort of back to equilibrium in the moment when that's going on, that's going to be the important thing in the long term if this is happening. You know, one thing is often so many people in the us, so many people worldwide have high blood pressure which means many people are on high blood pressure medicines. Right? and that's fine and it's important, however, because of this orthostatic hypotension issue, sometimes people who did have high blood pressure for many, many years and have not been on blood pressure medicine to lower it, right? The Parkinson's is actually underneath kind of resetting their set point and lowering their blood pressure. But this might not have been noticed. They may just see, you know, their primary or their cardiologist every once in a while. Any problems? No. Doing okay. Alright, keep on keeping on, keep that prescription for lisinopril, metoprolol, whatever the blood pressure medicine is, we keep it on. Except if the person is starting to kind of bottom out and have these low-pressure episodes, you may be able to graduate from needing the high blood pressure medicines. So, sometimes while there are medicines that we use to bring up the floor kind of and try to prevent the bottoming out episodes, the simplest thing sometimes is, hey, you're on something that is lowering you, let's take that away.

And so, sometimes we can just get rid of a medicine rather than adding something on. Yeah. Hydration is huge and the opposite of what we do for high blood pressure. So, high blood pressure, we know that excessive salt intake is a problem. Salt raises blood pressure. Yeah. So, if blood pressure is low, people are often like, wait, what? You're telling me to consume more salt? Yes. Because we want to bring blood pressure up and salt pulls fluid into the blood vessels. So, this can be a really tricky thing for a lot of people to navigate because we've done a great job and public health of raising people's awareness of the risks of high blood pressure, which are real. But what this means is if every single day you have high blood pressure, that increases your risk 10 to 20 years from now of heart attack or stroke.

But if today your blood pressure is relatively normal or on the low side of normal and every time you stand up, you drop your blood pressure 20 or 30 points and you're at risk of a fall. That fall that could happen today is a much greater risk than the possible long-term risk 10 or 20 years from now. So, I, you know, hear these like gears grinding up against each other, kind of like what? But I thought high blood pressure, we can't stop taking the high blood pressure meds. They had high blood pressure. Yes. And like a lot of things in Parkinson's, as time goes on, there is this trade off of, you know, okay, what was a big, you know, important thing before actually like is less of an issue now, but this other thing is more of an issue. And so, we're going to turn our focus and treat this and maybe we don't need to treat this other thing anymore.

Polly Dawkins:

Well, we've got so many more things to talk about with nOH, but I also know we've got questions that the audience has asked us before we move into answering a few questions that Mel is going to rejoin us and ask those questions. Anything that I've forgotten to ask about nOH or that's important to dive into?

Jori Fleisher:

I think just making sure if it's happening, if your loved one is passing out or if your loved one is feeling lightheaded, tell their neurologist. If you can, if you have a home blood pressure cuff, if you can get a home blood pressure cuff, the way to monitor for this is basically have your loved one either start by lying flat in bed, lay still be in one position for two minutes, check blood pressure like that, write down the blood pressure, write down the heart rate, have them sit up, come to rest for two minutes, just hang out there and then check blood pressure and heart rate sitting up, write that down and then have them stand up and same thing, wait two minutes of standing, check the blood pressure, write down blood pressure and heart rate. What we're looking for is if there's consistently a 20-point drop, you know, not every single day necessarily, but if we see that there's this big drop in that top number or a 10-point drop in the bottom number that is suggestive of orthostatic hypotension or nOH.

And again, there are lots of things that we can do to treat it. So, sometimes there are just non-medication things. Sometimes changing the position that someone sleeps in bed, even though it sounds counterintuitive, sleeping with your head elevated in bed. So, on like a wedge triangle shaped pillow can be really helpful for helping the blood pressure not to drop during the day. Sometimes compression garments, so compression stockings sometimes, sometimes an abdominal binder, which is a very fancy way to say sort of a girdle kind of thing. Oh, Spanx basically a girdle Spanx. Yeah. So, those actually really can help because essentially, if the blood vessels aren't going to smush all that blood back up towards the center of the body, well then, we'll kind of do it externally. Right. So, there are things that we can do before jumping straight to medication, but this is one of those symptoms that is there is often unrecognized is treatable.

And if your person with Parkinson's is constantly dropping their blood pressure, sometimes that may be a cause for their motor fluctuations. Sometimes that may be a cause for their cognitive fluctuations. If your brain is not getting the blood flow that it needs, you're not going to think as straight and as well as you would if it was getting full pressure. Right. So, this is one of those, eh, this seems less obvious kind of symptoms but actually seems like it's contributing to many other symptoms being worse. And so, we can kind of hit multiple birds with one stone if we recognize and treat nOH.

Polly Dawkins:



And I've read, correct me on this jury, that between 30 and 50%, as many as 50% of people with Parkinson's experience N nOH,

Jori Fleisher:

Yeah. It may be even higher as time goes on. Especially, I know we talked like way back when that people in later stages often, you know, aren't represented in research. But from our home visits, so many of our folks in stage four and stage five, we were the ones diagnosing them with nOH for the first time. Even though to talk with them, they've been having some, you know, those symptoms for years. So, I think it is probably even more common than we recognize. But again, treatable if we recognize it. It's treatable.

Polly Dawkins:

As you said there, as well as the non-pharmacological treatments. We've talked about hydration and bind abdominal binders and others. Exercise pro. Does exercise help nOH?

Jori Fleisher:

It can be tricky Sometimes that can be a thing that prompts people to drop their blood pressure. So, we have to be really careful about that and just know and adjust for that person. But yes, there are several different categories of medicines that people can use to help sort of bring up the floor and try to prevent people from bottoming out and dropping their pressure so much. So, we have lots of different things in the toolkit. We just need to know, hey, you need this toolkit.

Polly Dawkins:

Oh, my goodness. It's hard to believe two hours because for me has flown by, but probably not for folks on the other end.

Jori Fleisher:

I hope this has been informative. I had the, I had the chat close, so people were going, man, she needs to stop talking about poop. I missed it. Sorry.

Polly Dawkins:

No,

Melani Dizon:

No. That didn't happen at all.

Polly Dawkins:

Yeah. So, Mel, are there outstanding sort of universal questions that we could address today?

Melani Dizon:

I think that the big one of the ones, a lot of them were quite specific, but one was on smartwatches and falls and joy. Do you have a much experience or insight into whether those are helpful or, you know,

Jori Fleisher:

I think on the research side, there's a lot of research going on into this. People are studying them a lot. I think it's still kind of up for grabs, you know, is there one that's necessarily better than another? I don't know. I'll say on the clinical side, I do have a lot of folks who, you know, have a Fitbit, or have an Apple watch if it's something that has sort of that fall detection that's enabled, it's not perfect necessarily, but it's another layer, right? It's kind of like an insurance policy. I have some folks where, you know, they don't want a medical alert system. They will not, will not, will not, but they'll wear an Apple watch, right? Or they'll, you know, they'll wear something else that looks like it's not a medical device but can be used for those purposes. So, you know, I have recommended to my own family in situations where I'm worried about people falling. I've actually seen a family member fall while wearing a device and I was like, what is that noise? And it was their Apple watch going off and detecting their fall. So, well done. Yeah.

The machine worked as it was supposed to, but is there enough evidence out there to say, you know, everyone should go out there and get one? Absolutely not. I think, you know, they're not cheap. And it has to be something that you're going to use and feel comfortable with.

Melani Dizon:

Right. And then the other question, we did talk about the shuffling in the fast, you know, the fast walking, which is fascination, which is another way of saying it, but somebody would love for you to talk a little bit, is, do you have anything else? I mean, we did talk about like things to do, but what could you do for somebody dealing with that and explain fascination for people who it's just shuffling, but they're not, they don't have that word, right? That term.

Yeah. So, fascination is often when it's almost like the top half of the body and the bottom half of the body are set on different speeds. So, it almost looks like for many people, their front will sort of pitch forward and their feet are trying to catch up to them and they're racing. So, someone might be, you know, starting to walk and as they're walking, they're getting faster and faster and faster and faster, and they're almost taking these tiny, tiny, short shuffling steps. But their feet are just kind of moving, really, really fast and they can't catch their balance. So, often people will kind of go into a wall or they'll find themselves sort of reaching for something

almost to, they can't put the brakes on themselves, so they're looking for something safe to bump into. Right. And obviously that can be really dangerous because they're bumping into things, they're not able to catch themselves.

So, some physical therapy sometimes that can be really effective. The challenge is sometimes fascination can happen, you know, as we get into later stages. If the person has both ion and significant cognitive impairment, they might do really well in a physical therapy session where therapist is right there and is like, okay, you know, come on Joe, do this thing. And Joe might be able to do it in that moment, but if they've got a lot of cognitive impairment, they might not be able to retain that information and that strategy. So, sometimes then it's another thing that the care partners sort of tasked with being that external coach of, you know, do this is happening, do this, do this. So, sometimes, you know, physical therapy can help. Sometimes an assistive device can be really helpful in this situation. So, canes do not tend to be great options in people with Parkinson's.

Jori Fleisher:

They often are more of a fall risk than if the person was walking without anything at all. And that's because figuring out what you're supposed to do, where am I putting it? Looking down at the ground, paying attention. What, how am I swinging this leg or this leg with this? That is a ton of multitasking. That's almost the whole National Guard has been redeployed to cane management instead of walking and balance management. And so, for people with fascination, often a walker and especially a heavier duty walker can be really helpful because it kind of grounds them a little bit more. So, there's something out there not endorsing any like one particular thing, but there's something called the U-step walker. It's really designed for people who have action and freezing of because it's heavier duty.

It is hard to put it into the trunk of your car. It is hard to get on public transportation. It's doable, but it's hard. It's heavy, which means if the person with Parkinson's whose fascinating starts to race really quickly, number one, there's just more drag because it's heavier and harder to push. And instead of having the usual hand brakes, the hand brakes are actually reverse engineered. Meaning if they let go, it stops. So, the brakes are on when they release. And so, that can basically, you can let the walker help stop you instead of trying to catch the walker racing out in front. So, that can be really helpful for some people. I see. The question about walking sticks depends on the person. I have folks who've used those really successfully sort of trekking poles or walking sticks. I think seeing a physical therapist who knows how to use them and knows how to train someone with Parkinson's on how to use them, like, don't just show up to your outdoor store grab some random sticks and, you know, think that you're good. Get the equipment through someone, with someone who knows how to teach you how to use it safely. But for, for certain people, those can be really effective.

Polly Dawkins:



All right. We have, it's the end of our session. I am sure you've got a few homework ideas for people to try out about constipation, lightheadedness, exercise, anything that you want people to go away in the next couple of days and try.

Jori Fleisher:

Yes. If you do nothing else, what is some kind of exercise for you that you can do this week? Some form of moving your body that you will enjoy and that will give you a moment of respite and a moment of peace and hopefully a moment of joy. Do that if nothing else.

Beyond that, you know, if you can talk with your loved one about exercise or how their bowels have been or, you know, can they hydrate or are they feeling lightheaded. Right? You can't do all of it. We know you can't do all of it. We are sort of, you know, giving you the fire hose of information. Pick one thing, right? And if that one thing is just you exercise one time more this week than you would've otherwise, even if that's a total of one time, that's awesome. You

Polly Dawkins:

Being the chiropractor, yes.

Jori Fleisher:

Being you, being the care partner, yes. Everything else is just extra on top. Right? If you can get your loved one to exercise with you, if you can get your loved one to exercise while you're doing your own thing. Bonus points, advanced placement.

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