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Speaker 1: Welcome to a recap of our latest third Thursday webinar. Hear directly from expert panelists as they discuss Parkinson's research and answer your questions about living with the disease. Join us live next time by registering for an upcoming webinar at michaeljfox.org.

Becca Miller: Hi everyone. We're so excited to have you join us for this webinar, One Step at a Time: Managing Gait and Balance Issues in Parkinson's. I'm Becca Miller. I am a person living with Parkinson's. I was diagnosed when I was in my late 30s. My daughter was nine months old. I am currently a single mom working as a psychologist at the Yale University School of Medicine, and I'm a member of the Michael J. Fox Foundation Patient Council. In September of 2021, I had DBS and have been learning to navigate my disease after this procedure.

One of the best pieces of advice I received when I was diagnosed was to take control of my disease so it didn't take control of me. As we know, PD impacts our mobility in big and small ways. Increasingly we're gaining understanding of therapies and techniques that can help us improve our gait and balance, and tips as well that can help inform care partners on how to support us. That is what our expert panel is here to share with you all today. So we've got a lot to get to, so let's get started.

First, let's introduce our panelists. We're so lucky to have three experts here with us today. From the clinical perspective, we have Dr. Alfonso Fasano. He's a Professor and Chair of Neuromodulation and Multidisciplinary Care at the University of Toronto.

More from the research perspective, we have Dr. Anat Mirelman. She's an Associate Professor at the Sackler School of Medicine at Tel Aviv University.

Giving us both the research and the physical therapy perspective is Dr. Terry Ellis, who's an Associate Professor and the Chair of the Department of Physical Therapy at Boston University, as well as the Director for the Center of Neurorehabilitation.

Welcome everyone, it's so great to have you here today. How does Parkinson's affect gait imbalance? I'll say for myself, that one of my first symptoms was a foot drag and that was something that was with me for years, starting out very slowly and then increasing. Honestly, I first attributed it to laziness that I just wouldn't pick up my foot, which is, in retrospect, really kind of strange. But when things come on gradually these things happen. Can you talk a little bit about just how Parkinson's affects gait and balance? Alfonso, do you want to start?

Dr. Alfonso Fasano: Yeah, sure. With pleasure. Thanks for having me. Hi everyone. This is an important question, and the answer, in theory, will be very long. I'll try to make it simple, also because it depends on what stage in the disease we're talking about these problems.

But in general, in Parkinson's disease, there's an inability to produce ample movements or large movements. For this reason, one of the early signs of gait involvement is short steps, and sometimes these short steps become so short, and also, the ability of the person to elevate the foot is impaired as actually described by you as well. This becomes more of a shuffling type of gait. They can also lead to falls quite soon because of tripping, simple like that. Also, when doing stairs, if the elevation of the foot is not big enough.

So this is very early signs. Actually, even earlier than this is a reduction of the arm swinging. When we walk, we move our arms and a very early sign is actually a reduction of this movement, especially on one side.

Often people happen to see orthopedic surgeons initially, because they have shoulder issues. And that's actually coming from an inflammation and arthritis of the joints because this movement is lost, it's been lost for a few years and therefore there's not enough lubrication of the joint during walking.

Over time, these problems can worsen, and freezing of gait is a big issue. We'll talk about it, and also the different phenomenology of freezing of gait.

And also balance can be affected. Balance is a more complex motor strategy because it's actually tapping into other functions. In order to be in balance, we need to be focused. Our attention needs to be there. We should be careful especially with what task. But balance also relies on our ability to move our legs. If we are per to beat it, if there's a mechanical push, for example, on our body, sometimes a way we have to keep our balance is just to step, and stepping we don't fall. So this is actually a very nice example of how gait and balance usually go together. And sometimes to fix balance, we need to fix gait.

Becca Miller: And that reminds me of every time I go to the neurologist, the neurologist is pulling me.

Dr. Alfonso Fasano: Yeah, actually this is an important point. So what you're describing is the so-called pull test. It is a test that was invented many years ago. And there are online actually very nice historical videos of David Marsden, the founders of this field, when he explains how to do a proper pull test. Pull test has to be strong enough because we want to perturbate the person center of mass. So we want the body to be pushed enough so that we can see the reaction of the body to avoid a fall.

There's a reason why this is done pulling backwards, and this is actually related to one of the questions I have seen in the chat box. The natural tendency of

balanced problems in Parkinson's disease is retropulsion. So people tend to go backwards. We have issues especially in the anterior posterior axis, so we tend to fall forward or backwards in this disease, not so much in the laterality axis.

And this is why people with Parkinson's can actually ride a bicycle, because to ride a bicycle you need to be challenged on this type of laterality. So this is what we call the medial lateral axis and that's why they can do it. Instead, it's more difficult to keep the balance in the anterior posterior axis. That's why we do the pull test.

So this is just to say, and that's something else that we'll discuss I'm sure later today, that there is also a lot of compensation that the body puts in place. I want to just give you two examples, when it comes to balance the fact that some people lean forward, this is something called camptocormia. It's something that can happen in Parkinson's. To some researchers, this is actually a mechanism of protection. Because if you're leaning forward, the chance to go backwards is reduced. And we see this often after physiotherapy, because some people have a better posture yet they start falling more backwards because their posture has improved.

And the other example of compensation that I can think of is the cadence. Cadence indicates how many steps we can do per minute. And I mentioned already the step length is reduced, but the number of steps per minute is not reduced. Actually, it can be modulated. So people can actually use that to compensate. That's why in order to keep a certain speed, people tend to have more steps with a short step length. That's compensation, that's good. But sometimes this leads to a vicious circle where these steps become shorter and shorter and faster and faster as the walking progresses. And that's not good. So that's a bad compensation.

But I'll pause here because I know I throw a lot of stuff in this answer. I will need to address one by one, these different aspects, as we go forward.

Becca Miller:

This is great. Anat, I wonder if you want to share with us a little bit how the evolution of gait impairment over time with the progression of the disease.

Dr. Anat Mirelman:

Sure. Hi everyone, I'm Anat. So first of all, as you mentioned and as Alfonso mentioned, in Parkinson everything is gradual. So it starts off very minor and just accumulates over time. And we need to remember that gait disorders are not similar throughout the disease, but they're not similar also between individuals. They vary quite extensively. And that has to do also with how a person was, if he was mobile, very mobile, age also affected. So there's many, many additional aspects to gait disorders and Parkinson's disease, they are not just the disease.

But in general, when we're talking about early stages of the disease, we will find asymmetrical behavior. So something that is vary, we can see the short steps,

that were discussed here, more on one side, the arm swing in one side, and then once the disease progresses, we will see a more symmetrical behavior that also affects rotation of the trunk. So this rotation of the trunk will create even a more shorter and slower kind of walking movement.

And with a progression of the disease, we will see additional issues that come off from the biomechanics of that impaired walking. And these relate to freezing of gait, for example, the inability to actually move or the feeling that the feet are glued to the ground.

And also in addition, we will see falls. And this relates to the balance issues that were mentioned here by Alfonso, but also to the real challenge of the body of the biomechanics with the short steps and the inability to actually correct movement changes, or imbalances, along the way.

I think we need to also mention that it might not be the case for everyone. Not everything will appear for everyone. And it's really important to listen to your own body and really describe to your physician what is bothersome to you in order to actually define the treatment approach that is personalized and really will treat the problems that you have. So the aim is to provide, at the end, personalized therapy.

Becca Miller: That's great. And I wonder, jumping in with a question from the audience, and maybe Terry, this is something you could field, they're asking can weight training be something that improves balance?

Dr. Terry Ellis: Yeah, I can answer that. Well, thank you for having me. It's a pleasure to be here. In general, there have been strength training, or resistance training studies, that have shown that have led to improvements in balance in people with Parkinson's disease. It's one aspect of a treatment plan that can help with balance. There are other aspects, but the weight training can help with the, sort of what Alfonso was saying earlier, people with Parkinson's have difficulty turning on their muscles sort of fast enough and with enough force to take a big step, for example, to prevent the fall.

These weight training exercises aren't going to absolutely prevent falling, but they can help improve a response to a perturbation and help to reduce the frequency of falling. So it's one aspect of an exercise program that can help with balance.

Becca Miller: That's a really nice transition to our next slide, which is to talk more about falls. And Terry, I wonder if you could share the guidelines for assessing fall risk and how you do a home safety evaluation.

Dr. Terry Ellis: I can talk about a couple of things. I think one reason, one benefit of people seeing a physical therapist when they have walking in balance problems, is that a physical therapist can spend a whole session, a whole sort of 45 minutes to an

hour session, really going in more depth with trying to figure out what's wrong with the balance, or walking, for this particular individual. Because like Anat was saying earlier, there's lots of variability in what can go wrong with balance and walking among people with Parkinson's disease.

So a physical therapist will administer a lot of standardized tests that can be done. For example, imbalance, standardized tests that look at different aspects of balance. So some people might have more trouble with balance when they're reaching down to the floor or reaching up overhead versus, for example, being perturbed or nudged or some quick movement that leads to a fall.

And so by administering standardized tests, the physical therapist can help identify what aspects of balance are particularly problematic for this person. And that helps the physical therapist then create an exercise program that's going to be tailored to those aspects of balance.

And the similar thing with walking, we do all kinds of walking measures. We measure walking distance and walking speed, and we look at the quality of walking. Sometimes we might even ask people to wear some sensors on their body and wear them at home for a week and come back in the next week so that we can take the data from the sensors to understand how much walking did somebody do, or at what intensity. And then even looking at some aspects of the quality of walking. And from all that data, using that data, then we can create this individualized exercise program with the goal of improving walking outcomes.

... and particular aspects of balance that hopefully lead to a reduction in fall risk.

In terms of assessing people's homes, I mean, people who are spending a lot of time at home, and most of their falls happen in home, then it might be a great idea to have a physical therapist or an occupational therapist come in the home and do a falls risk assessment. And that has a lot to do with identifying certain environmental barriers or environmental triggers in the home that might increase risk of falling, or it can be examining strategies that people are using when they move in the kitchen or the bathroom, for example, and there might be some different strategies that people can employ to reduce their risk of falling. Does that help to answer your question?

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Becca Miller: For sure. Mm-hmm.

Dr. Alfonso Fasano: Since we're talking about balance and gait, I think moving forward ... And I made an example of how actually falls risk has to do not just with balance but also with gait. I think we should take a step back and describe a bit more of the two major type of problem with walking than people with Parkinson's might have. We have actually a slide where you can see that, yeah, in general, there is

bradykinesia and hypokinesia, which is classic and it's one of the early signs I mentioned before. Bradykinesia means moving slowly. It comes from Greek. Hypokinesia means moving in the small steps in this regard, so it's the amplitude of the motion. And that's something that we see, something that has to do a lot with our dopaminergic cells in the brain, and therefore it can improve with specific treatments, for example, levodopa.

But what's really important to discuss a bit more is freezing of gait, and actually, Anat is an expert of freezing of gait, and she can probably give us an overview of the different types of freezing and what triggers it. Let's start with the description, actually, what freezing of gait really is.

Becca Miller:

That'd be great, Anat, if you could do that?

Dr. Anat Mirelman:

From a clinical perspective, really, what a patient will describe to us is that he feels that the feet are really glued to the ground. So, the inability to actually take a step, and this can be an inability in which there is total non-movement, so akinesia, what we call akinesia, or even a trembling in place, a feeling that they're trying to move the leg but they're not able to. And this is actually a very, very interesting phenomenon and people have been studying it for quite a while. But I think there's a lot of questions and a lot of explanations that we still don't know.

But currently there are several theories that suggest, for example, that there might be triggers or there might be connections between neural networks that actually are involved in this situation. So if we're talking ... If Alfonso was sharing the issue with automaticity or problems with basal ganglia that create ... or the neurodegenerative process that create this problem in automaticity, then one example, one theory that relates to freezing of gait is called the cognitive theory in which it suggests that because of the lack of automaticity, people use different compensations or different networks to actually compensate for this lack of automaticity. Meaning, thinking, being more aware of walking, for example. And when these fail, we see a freeze. We see a problem with gait. So, this is one example or theory.

Another one is, for example, the stress or anxiety theory, which can explain why people tend to freeze in narrow passages or narrow hallways, or when going through a door, or when they're trying to reach their phone when it's ringing, and so forth. So, when there is a trigger that relates to either time or space, this might be related to the anxiety theory.

There's also theories that relate to visual-spatial processing, and other connections might explain it. But what we see in general is that there are several different types or subtypes of freezing of gait. We see people who freeze when they're off medication, and people who freeze when they're on medication. These are two examples of subtypes. And these actually are really important distinguishers, because if this is a person who is freezing off

medication, potentially, by providing timely and accurate dose of therapy, then we can avoid this freeze of gait issue.

When freezing of gait, it happens when on medication, then maybe the underlying mechanism is a bit different and it's not dopaminergic, and we need to think, "What exactly triggers it?" and maybe provide a non-pharmacological treatment. That can be, for example, cueing, and we know that cueing might be very helpful. When we're talking about cueing, that can be a strategy such as visual cuing by providing, for example, lines on the floor when walking, or an auditory cue like a metronome, giving some external feedback or external cueing for walking and taking a bigger step.

In any case, similar to what we said earlier about walking, here too, it's very personalized. So, we think that in the beginning, freezing might be very distinct for each person, and the triggers are very distinct for each person. And when the disease progresses, it might be a mixture of things, but initially, it might be very distinct for each person. And it's a good thing to maybe look at the triggers and look at exactly when this happens, in what environment this happens, and what is the situation that it occurs in.

Becca Miller: Wow, that's such a great description, and so important to have it be personalized is what I'm hearing. And I wonder, there was a question from the audience about the difference between freezing as we've been talking about, and festination? Alfonso, could you ...

Dr. Alfonso Fasano: Yeah, festination.

Becca Miller: Festination.

Dr. Alfonso Fasano: Fenestration is a little more ... I would say they're both dangerous, fenestration and festination. But we are talking about festination now, and it's a obscure term, and I realize that anytime I have this type of webinars or I speak to people with the disease, it's a common question. So just to make it simple, they belong to the same disorder, and that's why we often talk about it at the same time.

Freezing is basically when your feet are frozen, and it's, in a way, a natural reaction that the body has. Think about when all of a sudden you find a, I don't know, an animal in front of you, and you pose, you freeze. That's actually a natural function that we have. Unfortunately, in Parkinson's disease, this happens all of a sudden. That's why it often causes falls while there's ongoing walking or turning or passing doorways, so it's a motor block. That's the way we call it. So, no movement.

Festination comes from the same pathological process most likely in the brain, but there is no motor block. It's quite the opposite, so people keep on walking faster and faster and faster, often leaning forward. And this increase of the cadence that I mentioned before happens, short steps, always shorter and

shorter, fast-paced gait, but no motor blocks. And that's why this can be quite dangerous, because it feels like they cannot stop themselves, and often the only way they have to stop themselves is either holding onto something, landing on the wall, or unfortunately, sometimes even landing on the floor. Sometimes, the patient actually falls on purpose to stop this propulsion. So, festination is the same process of freezing of gait, this constant stepping, without the motor block. Because in freezing, often we see constant stepping and then the patient, the person with Parkinson's, stops, which is lacking in festination. So these are different. Festination is rarer than freezing, but it's still very important to be discussed and quite disabling. And to some extent the approach is similar in terms of treatment.

I also noticed in the chat box a question about doorway, and this is something not already mentioned. Just curiosity, in case people wonder, we now know which ones are the risk factors for this doorway problem. It turns out that people with the disease more prominent on the left side of the body tend to have this problem more often. And this is because this means that most of the pathologies is on the right brain, and the right brain is the part of the brain in charge of visual navigation. So, the problem here is with interpreting what's happening, and the visual flow as we go towards a doorway, in this case.

And lastly, in case people wonder, we often don't see these things in the clinic. We rely on what people say. Festination is a typical example, but also doorway freezing to some extent. And often, people with freezing of gait or festination don't have the problem in clinic. I often see the spouse or the person with the problem almost complaining, "You are pretending to have this problem then, because when you come to see the doctor, you don't have this issue." And actually that's the way it works. The brain in certain circumstances under the stress of the appointment, in wide open space with a lot of light, no furniture, works better. That's why we don't see freezing in the clinic. It doesn't mean that it's not a real problem, and that's why we need to educate people like we are doing today because we rely on the description you give us of what happens at home.

- Becca Miller: It's like when I take my car to the mechanic and the clunk stops, right? But-
- Dr. Alfonso Fasano: Exactly the same analogy I use. Yeah.
- Becca Miller: Yeah. No, I mean my daughter gets so frustrated with me because I'll be walking with her and I cannot say the word. I'll start going so fast, she's like, "Come on, stop, stop, stop," but I can't make myself stop. I'm just kind of shuffling along pretty quickly.
- Dr. Alfonso Fasano: This is something we see often in DBS. Actually, most of the festination cases I see is in DBS patients. My interpretation is that DBS is good at treating the motor blocks, or freezing of gait improves, but sometimes it's not just there to

improve everything. So, you see a little bit of the problem in the form of festination.

Becca Miller: I wonder what each of you has recommendations for footwear. It's come up in the audience, and I would love to know as well, what you recommend or not recommend along with assisted devices like canes, et cetera.

Dr. Terry Ellis: Yeah, I can talk a little bit about that. Footwear is a little tricky. Some people say, "Well, you want to have something that provides good support and has a lot of friction and is stable," which can be good for some people. But in some people, the thick rubber can also be sticky and be difficult to move your leg forward. And for some others, a more smooth surface can be helpful in trying to take a bigger step, yet you don't want it to be so smooth that it's slippery. So again, we have to sort of individualize it depending on the type of gait problem that a person is presenting with. It's not sort of a one-size-fits-all recommendation. And then there was a second part to your question. There was the shoes, and-

Becca Miller: Assistive devices like canes.

Dr. Anat Mirelman: Oh, their assistive device.

Dr. Terry Ellis: Yeah, we get that a lot. That's a very, very common question. Again, it is individualized to the person, but they tend not to be very helpful in people with Parkinson's disease. For example, people with Parkinson's lose automaticity of movement, and then they're thinking about movement. So adding another aspect of movement to the situation, not only do you have to move your body forward, but now you have to move some sort of cane or walker forward? That can be difficult.

For some people that are really falling and really need some sort of assistance, and this tends to be in the more later stages, sometimes a walker can be helpful. But the kind on wheels could be more helpful for some because if you don't have to pick it up and move it and think about it so much. Yet certainly if you're festinating, you don't want a walker on wheels.

So it's very, again, it has to be very individualized to the person's presentation. And that I would really recommend people go see a physical therapist with that question, "Hey, should I be using a cane or a walker? Would that help me or hinder?" And it's an important question that requires a thorough evaluation. What I wouldn't recommend is, what I see is, people go in the pharmacy and buy one and start using it, and that's just not a good idea. So, consulting with an expert to really get a thorough evaluation is the way to go.

Becca Miller: What would you say about walking poles? A lot of questions have come up about those.

Dr. Terry Ellis: Yeah, I mean as again, for some people, and for some people that can be used as a form of exercise, helping to exercise, helping to walk faster, to move the arms, to get the heart rate up. But again, it really needs to be individualized to the person. Parkinson's, if we can say anything, it's definitely not a one-size-fits-all recommendations.

Becca Miller: So individualizing, that's really good advice. I wonder, I know for myself it was really helpful for me

listening to Alan Alda, who I'm a big fan of, when he talked about marching and thinking about marching to music. That's been really helpful to me. Can you say more about how that works and as a tip and -

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Dr. Terry Ellis: Yeah, I can talk a little bit about this. Does somebody else want to jump in or -

Dr. Anat Mirelman: Just to say that it's a form of, you know, we just talked about cuing as a form of treatment for freezing of gait. So basically if we think about music or cuing, they bypass the problem by providing something external that can give you a rhythm instead of the rhythm that is not working from internal sources. So this is why it kind of initiates the movement better and it allows you to follow that rhythm and follow that kind of pace and gives people a lot more mobility in a sense. And it's been used also as an assisted device in a sense, by using it in the home or in areas that are difficult for the person. And Terry can talk about treatment with cuing and music.

Dr. Terry Ellis: Yeah, there's all kinds of different ways cues can be used or strategies or cues can be used and it depends what the problem is. If the problem is gait initiation or starting walking, then something like marching can be a good way to help with that, with initiating walking. If the problem is gradual slowing of walking and taking smaller steps as the walking continues, then things like using a metronome or music, some sort of external stimulus where the person can entrain or lock on to that external beat, that can be very helpful with something like a more long distance, continuous walking over time.

It helps keep the steps more regular, a little bigger, those types of things. We talked about the sort of lines on the floor. Sometimes a line on a threshold through the doorway can help provide a cue to step over that threshold. Lines through a doorway as a strategy to help people walk through a doorway. I find that when people look across the lines through the doorway, so the attention is actually focused through the doorway rather than on the doorway, the cues can help that focus. So there's lots of different cues and strategies that people with Parkinson's can use. I've learned many from people with Parkinson's, living with Parkinson's, have taught me lots of cues and so it's a sharing of information and trial and error to figure out, okay, what works best for you in this situation?

Dr. Anat Mirelman: Actually, Robert in the chat is actually saying that he has freezing and he finds that the only thing that actually works for him is crutches. So we learn from patients what works best and there's so many strategies.

Dr. Alfonso Fasano: Just like a note, word of caution about this because it's true, every person has different strategies, but as you heard already, it's difficult to generalize. I'll give you an example. I met once a man who happened to turn just jumping. So he figured that jumping was better for him to turn, but that was his personal compensation strategy. It was working for him. It didn't cause any fault, but from that to going around saying, "Oh, if you have problems with turning just jump," it's a big gap and you don't want to do that.

So for the same reason any compensation strategies that you can hear about even today, don't assume that necessarily you got to do that because we can actually be causing false and it can be actually a dual task. Some people, instead of being helped by these devices are, as you heard, already, are distracted by these devices and therefore their automaticity is even more impaired because they need to deal also with, I don't know, the pole and [inaudible 00:34:32]. Yeah, everybody has their own and it's not easy to jump from one person to another with respect to strategies, but that's also the beauty of our brain. Our brain has incredible ways to figure out things out. And with Bas Blum, once we saw a patient that touches the temple and with that strategy can move, obviously it doesn't work all the time, but that was actually an interesting observation that led to a publication with the title of superficial Brain Stimulation to overcome Freezing of gait, which was kind of clever way to describe the strategy.

Becca Miller: So I guess the take home here is your mileage may vary and be creative and kind of test them out.

Dr. Alfonso Fasano: Yeah.

Becca Miller: These are great important principles. I wonder about thinking about kind of wearables and devices, all those kinds of things. What are your recommendations? Lots of talk in the chat about in the Q and A about that. Terry, do you want to start?

Dr. Terry Ellis: Yeah. A lot of people come to us wearing Fitbit and Apple watches and all different kinds of things, and in general those can be really helpful in encouraging people to be more active. Monitoring how active you are and how many steps you're taking a day can be helpful in motivating people to do more. It really depends on people's gait patterns, how accurate these are, because sometimes if your gait is really slow or very shuffling, then it's not clear whether these devices can actually measure a step accurately. So normally when we take a big step and we land on our heel and it's very rhythmic, these devices are pretty good at identifying steps and counting them. But for some

people a really slow pattern or really shuffling pattern or certainly freezing of gait, this is, they're probably not as accurate.

Again, it really depends. I mean, to some degree you can check this and count your steps and see what the device is picking up and determine whether that is, whether it's working for you. And a physical therapist can help with that as well. When we measure gait and people with Parkinson's in research for example, we use research grade monitors or different monitors that have been validated and are usually more accurate in measuring different aspects of walking. But these commercially available devices, again for someone early on that has really mild gait problems, they're probably pretty good. But with more moderate to severe gait disturbances, they may not be as accurate.

Becca Miller: Okay. So the devices may not work as well. I know I would trick my device sometimes by just shaking my arm and having it record some steps.

Dr. Terry Ellis: That's another great point is it can measure if you wear it on the wrist, it can pick up things like tremor and dyskinesia can also lead to erroneous counting of steps. So there are other factors that can be counted as steps that of course aren't steps.

Becca Miller: Dr. Anat or Alfonso. Anything you wanted to add on the wearables?

Alfonso Fasano: Not necessarily. Anat is an expert. I just want to say that wearables are measuring some motion. So I always see too much hype around wearables. They can be useful, but it depends how you use them and what you want to them, what question you want them to answer. If you're talking about something called gamification, so you are actually playing and actually using these wearables to keep track of your mobility to motivate you to do more, that's a useful way to use them. But often they don't really add much in my experience, but Anat does research on this, so she might have a different -

Dr. Anat Mirelman: No, but I agree with this comment. In essence it depends on what the question is and in research we're looking for specific things to better understand the mechanism, to better understand the variance between people and maybe to predict things like who will fall, who will develop freezing of gate in the future. But when using commercially available devices in the home, I mean I would regard them as something that is motivational. So for a behavioral aspect, how much I'm moving, looking at giving me some incentive to potentially do more, get out of the house and be more mobile. But I wouldn't take this as a too accurate or really depend on it. And as Alfonso said, there are also wearables that are used at for therapy or for cuing or for giving some mobility enhancers. But again, this needs to be evaluated for each person and as we said before, really therapy should be consulted with a therapist before using these devices alone.

Becca Miller: So there are a lot of questions coming up about DBS. I know for my myself, DBS has been hugely helpful and I feel really lucky about that. But in terms of gait, I have developed more kind of a shuffle or fenestration. I think that's how you say it, but that word is going to plague me. But I wonder if we could address the DBS question a little bit more.

Dr. Anat Mirelman: I just have a question. Becca, did you have freezing of gait before your DBS?

Becca Miller: No, and I still don't.

Dr. Alfonso Fasano: Well, I can probably take this one because I spent most of my day and I've spent most of my life at this point talking about the brain stimulation and using the brain stimulation to help people. I also seen in the chart that some people were wondering what DBS is simply put as a brain pacemaker. It consists of usually two electrodes, one per side, in inserted in certain strategic parts of the brain, connected with wires that run under the skin attached to a battery pack, a real pacemaker that is usually under the collar bone. So that's a stimulation of certain parts of the brain and it works. And that's the most important message probably about this. It works in well selected people. It's not something that you will do and you will have the same answer of the same effect across the board. No, it depends on the person.

It also depends on the target. There are two major targets in the brain subthalamic stimulation. So stimulation of a target called sub thalamus or globus polydus stimulation. So stimulation of another nucleus called globus polydus. The first one is usually the strongest, but it's also the one that can cause more problems if done not in the right person. That's usually the one that young people have because also allows medication reduction. But guess what, if you do it in the wrong person, one thing that you can easily see is speech, balancing, gait worsening after brain surgery, or even with the wrong stimulation parameters. So this is extremely relevant to today's topic because this type of DBS can help and it can help a lot because the effect mimics the effect of levodopa. But if it's done in a brain that is too frail, in a patient who is not the right candidate, you actually have the opposite effect.

This is why whatever we say today, as you heard the [inaudible 00:42:20] to be discussed with your own care provider. The other target global polydus is safer. Safer with respect to gait and balance. It's probably less effective on slowness. This is why medications are usually not reduced, but that's the target we choose. In Toronto for example, when we deal with people who are a bit more frail or they have already freezing of gait to begin with. So in short it works because it's a constant effect on the brain. It doesn't make any sense to do DBS early in the disease. It's very effective for motor fluctuations when the symptoms go up and down or for dyskinesia. So anytime your disease needs something that is constant, this is what you need. Deep brain stimulation. The only exception to this will probably be tremor, because tremor responds better to deep brain stimulation than medication. So some people go for deep brain

stimulation even when they don't have fluctuations or dyskinesia, but simply because they have a tremor. But everything has a price. So if not well selected you may end up with problems. And that's why you need to rely on what your care provider tells you.

Becca Miller: That was a great summary. So in terms of the effect of DBS on gait, then, if for a well chosen candidate, what do you think?

Dr. Alfonso Fasano: That's why we do levodopa challenge. The levodopa challenge is sometimes people ask me, okay, why do we need to do this? Meaning that they come to the hospital without medication taken without levodopa so that we can see how they do without medications. Then we give the medication and we see how much is the response to medication. As a rule of thumb, whatever problem improves with levodopa, it will improve with DBS. So that's why we do the levodopa challenge. So if someone has a freezing of gate that doesn't respond to medication, DBS has very little role. It can still help many other things tremors, stiffness, but it won't help freezing. So sometimes we do levodopa challenge also to tell the patient and the family what to expect from this procedure. Because a big problem with DBS is expectation. Very often people are disappointed after the procedure if these expectations are not set clear from the very beginning and levodopa challenge helps. In this case, particularly speaking as for freezing. To some extent also balance, even though that's more difficult to predict, we tend not to do too much DBS in people with a profound balance problem because DBS rarely helps.

Becca Miller: Thank you. So I wonder

from the audience, there's a lot of questions about different tips or tricks on helping with freezing or balance issues.

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Dr. Alfonso Fasano: Just two points, actually three points very quickly. First, sometimes medications don't help, make things worse. And keep that in mind, because you go see your neurologist, "Oh, freezing is still a problem." The neurologist, the natural tendency of every doctor, including myself, will be to give you higher doses. And that creates a vicious circle, where things get worse and worse and worse. Levodopa in rare cases can make freezing worse, for example.

The second thing is blood pressure. A big issue is low blood pressure, especially when you stand up quickly, you may feel a little dizzy, or even without feeling it right away, the blood pressure can drop over time, and that's an unrecognized cause for balance problems and falls. So always measure blood pressure, not just lying down or sitting, but also standing.

And finally, there was a comment about wheelchair in the chat, and I think it's an important point to address. We are not opposed to wheelchair, but they're

not always needed, thankfully, especially we want people to try to move as much as they can to keep active. Sometimes, wheelchair is needed for safety reason. There's no need to be worried about the stigma of wheelchair problem sometimes, because wheelchair can be used also during strategic moments of the day. For example, you use the wheelchair to go at the airport just for that long, usually walk that there is at the airport. You are in a wheelchair, and then, you forget about a wheelchair. You don't use it anymore when you're on the plane, when you are in the lounge, or whatever, because you don't need to walk for so long. So it's also a wise way to use a wheelchair. It's something useful. We don't always recommend to go there necessarily, but it can be safe for a whole perspective.

Becca Miller: I think that's so important. I love that you said not to disregard the stigma of it, because I think that it's really about keeping your quality of life and doing what you need to do to be able to keep on doing things, like travel and airports and the saving your energy in that kind of way is so great. I wonder if there are any other tips or tricks or particularly... Oh, I guess one other question that was coming up in the chat was about toe curling, and I guess that's dystonia and affecting your feet and how that can affect gait as well.

Dr. Alfonso Fasano: Yeah, so dystonia can respond to levodopa, but another easy way to treat dystonia is botulinum toxin injection in under your foot or in other muscles or the leg. And that can help the curling and that can in turn also helps gait.

Becca Miller: Great. Well, we're going to take a quick chance to talk about the PPMI. Just as a brief aside, to let folks know about the Parkinson's Progressive Markers Initiative by the Michael J. Fox Foundation. So they're currently recruiting folks to be a part of the study. So you can visit that website and sign up, so you can sign up yourself. Those without Parkinson's can also sign up. There's a free smell test that you can order, so check that out please. Because this is one of the ways that we can involve more people in research and spread awareness about Parkinson's. So I think, no, the time has just flown by, but I think we want to just see if there are any helpful tips and tricks and other recommendations that our panelists would have for the audience.

Dr. Terry Ellis: I see there's a couple questions on how to improve balance. And I think there's a few things. It's really important to take a history from the person that's experiencing balance problems, to identify the circumstances under which they lose their balance, that there might be falling. So that's really important. And then, we do a standardized assessment to determine, again, under what conditions people fall or lose their balance. And because that will then tailor the treatment. But in general, challenging balance is what's important to do, and there's lots of ways to do that. It can be done via participating in things like tai chi, for example. And there's dance, has been shown to improve balance. There are certain balance exercises that can be done. And so, it's not that one specific thing needs to be done or one type of exercise. It's just that, in general balance, needs to be challenged.

So the dosing has to be enough, and it has to be done continuously over time, not just a few days or a few weeks, and that's it. It has to be done over the long term. So again, what that means is that there's a lot of choice, and people can choose something that they like or that they are willing to do and adhere to over time. But it's nice also to get a full evaluation, so that you can tailor that specific intervention to the particular types of balance problems that you're experiencing.

Becca Miller: Great.

Dr. Anat Mirelman: I want to give another tip for the audience. We've been saying all along throughout this webinar that it's personalized and we need to keep in mind the person, but there is one tip, I think, that can be generalized to everybody, especially to those who are recently diagnosed. And it is that, if we start practicing or start doing exercise early, and if you maintain a good health and a good mobility with your body, you might be able to sustain it for a longer period of time. And this is important, because we know, from research, that early intervention now can have an effect on the disease progression. And potentially, we can delay any complications. And it goes also for falls.

One of the things that people often ask is, "how do I treat falls?" Well, the best way to treat falls is to avoid them and avoiding them by creating a better mobility capacity and sustaining the best balance that you have. And this needs to be started early, as Terry has said, and each one of you, of us, of everybody needs to find the thing that he loves to do, that he can maintain exercising for a long period of time. It doesn't have to be the same all the time. It can be different, and you can change throughout the course of the disease and throughout your life. But it needs to be consistent. You have to exercise. You have to be mobile at all times.

Dr. Terry Ellis: Dr. Start early before you even have the problem.

Anat Mirelman: That's exactly.

Dr. Terry Ellis: That's key. No matter what the problem is.

Dr. Alfonso Fasano: This is what I tell myself every morning when I get up. I always postpone it.

Becca Miller: Well, there's a lot of questions about this pain from toe curling. I wonder, we just have a couple minutes left, but I wonder, Alfonso, if you wanted to address that really quick.

Dr. Alfonso Fasano: The curling is dystonia usually. It responds well to shots of botulinum toxin or medications. Or dystonia can also affect the calf and also be painful, especially in the middle of the night. There are ways to minimize this with drugs, and again, botulinum toxin can be used. Yeah, no more than that. I think we should use this next few minutes to discuss the other tips. I've seen questions about

music therapy, that probably Terry and Annette can comment on. There's so many things, and let me just say once again that the most important thing is exercising. Really is it goes beyond DBS. Beyond medication. Is the real medication.

Dr. Anat Mirelman: Well, save your brain. I think maybe Terry, you can mention when to go to a physical therapist, when to start, how to find one.

Dr. Terry Ellis: Yeah, definitely. I think it's really important to establish your team early, your whole team, your neurologist, your therapist, your physical therapist, your speech language pathologist. I think, so we recommend people go see a physical therapist as soon as they're diagnosed. You want an exercise program that what the focus is on prevention and getting started early, making the lifestyle changes necessary to integrate exercise into your life, particularly at the beginning, when it's easiest and when you're most mobile and most able to benefit from an exercise program. And then, we recommend, just like you go back to see a neurologist every six months or whatever for a medication adjustment, it's important to go back to see a physical therapist every six months or annually to get an exercise adjustment. You can't just do one exercise program for life. It has to be adjusted and tailored, depending on how the disease is changing and how you are changing and what your goals are. So we recommend regular follow-up visits for that reason.

Becca Miller: That's such a great point. And just adjusting it to how your disease is progressing, how things are changing for you, and things changing in your life. I know, for me, that I go back and forth between being really good about exercise and then dropping off for a while and then, I need to kind of remotivate and come up with something new and go out with a friend or all different things that I can do to get myself to continue to exercise. Well, I just want to say thank you so much to each of you for all your wisdom and knowledge and contributions to the Parkinson's community and with the research and work that you do. Really, just so important. There's so many questions in the chat. I wish we could have another hour, but I know we have to wrap up in just a minute here. And so, I just want to say thank you, and any last comment that you each want to make?

Dr. Alfonso Fasano: Just thank you. It's been a pleasure, and education is really key. It's important that Michael J. Fox Foundation is giving us this opportunity.

Dr. Terry Ellis: Agreed, this is an important topic, and I'm glad we had the chance to discuss it amongst ourselves. I think it's something that doesn't get as much attention as some of the other aspects of Parkinson's, and this is a really important topic.

Becca Miller: Great. Thank you.

Dr. Anat Mirelman: And thank you, Becca. Thank you for moderating, and again, start early. Exercise.

Becca Miller: Thank you everybody.

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