



**The Victory Summit® Virtual Event:
The Parkinson's You Don't See: When Your
Autonomic System Goes Off-Track
"Autonomic Dysfunction and Regulation"
Davis Phinney Foundation**

Polly Dawkins (Executive Director, Davis Phinney Foundation):

As a quick background, let me tell you a little bit about Lucy Norcliffe-Kaufmann. May I call you Lucy for this?

Lucy Norcliffe-Kaufmann, PhD (Associate Professor, Department of Neurology and Department of Neuroscience and Physiology, NYU Grossman School of Medicine and Associate Director, Dysautonomia Center):

That's fine. Yes, of course.

Polly Dawkins:

Wonderful. Lucy has a PhD in physiology and is a highly regarded extensively published NIH funded expert in autonomic disorders, neurogenetics, and neurodegenerative diseases. And she's worked with people with Parkinson's for over 15 years and done so much research on non-motor autonomic features of Parkinson's. So, we're gonna dive into that. Today is gonna be a conversation between the two of us, and we're gonna go through what is autonomic dysfunction, what is the autonomic nervous system, and all through the different symptoms people may experience and really focusing on strategies, non-pharmacological strategies to deal with some of these symptoms. So welcome.

Lucy Norcliffe-Kaufmann:

Thank you, Polly.

Polly Dawkins:

And for those of you in the audience, you might not know that she's just recovering from knee surgery from skiing. So, this is her first day back at the office, and we're just really privileged to have you here. So, thank you.

Lucy Norcliffe-Kaufmann:

I'm delighted to be here.

Polly Dawkins:

Great. So, let's start off really high level. Tell us a bit about, what is the autonomic nervous system and what does it control in our body?

Lucy Norcliffe-Kaufmann:

So, the autonomic nervous system is a network of nerves that really control all the automatic functions of the body. The things we don't think about, like the control of the gut, the control of the breathing, the control of the heart rate, the blood pressure, the amount you sweat. And it really is a system of networks that you have these sensing nerves that signal to the brain that help keep the whole body in line in, in orthostasis, right, in check. So, what happens is when you detect that some that something inside your body has changed, it signals to the brain and the brain then coordinates back to the body to control the organs so that the organ functions are all regulated and that's the job of the autonomic nervous system. So, it goes on in the background without us consciously having it to control those actions.

Polly Dawkins:

Makes sense. So why does the autonomic nervous system get out of whack for say a person with Parkinson's, our audience?

Lucy Norcliffe-Kaufmann:

It's a really, it's an excellent question. And what we're basing on our current theories are, again, you know, this protein that you've probably well heard about, right, alpha-synuclein, which accumulates in the nerves in patients with Parkinson's disease and is likely to be involved in the death and destruction of those nerves. So, the same protein that is affecting the nerves in the brain that control motor function is also affecting those nerves that are running to the organs, controlling the organs. So, many times you see biopsy samples, for example, of the skin show deposits of alpha-synuclein, this rogue protein in the nerves innervating the blood vessels of the skin and the sweat glands. You see alpha-synuclein deposits around the nerves in the heart. So, it's really, you know, the same pathological process going on in the brain is also affecting the nerves in the, running to the organs, right the autonomic nerves. And then you also have some accumulation of that same protein in the areas of the brain that are involved in the control of the autonomic function. So, it's what we call, what we think of really as both a central problem inside the brain and a peripheral problem outside the brain in the body. Right. But it's those nerves that are being under siege, right by that protein and progressively injured.

Polly Dawkins:

Got it. Hmm. So that, that can affect many, many parts of the body.

Lucy Norcliffe-Kaufmann:

Exactly. And that's why this, the non-motor autonomic symptoms of Parkinson's can be so hard to put together because you have the organs are all innervated by these particular nerves, right. And some may be more affected than others, right? So, some patients may have terrible constipation. Others may have problems with blood pressure. Others may have very little problems whatsoever, but just notice, you know, that they may feel like occasionally like headed when they're standing up. Right. So, it's really the amount of autonomic problems that

people with Parkinson's disease have varies from patient to patients, but it's almost always present to some degree.

Polly Dawkins:

The earlier presentation by Dr. Fleisher, she mentioned, you know, symptoms being a bit like a menu at a cheesecake factory where you may never try all of the things on the cheesecake factory menu, but they could be there, they might be something for you to try and you may go back to cheesecake factory many times and never even try. And it sounds like these symptoms may affect some people with Parkinson's and some of the symptoms, but not others.

Lucy Norcliffe-Kaufmann:

That's exactly right. That's exactly right. And that's such a great analogy to think about it in that way, because you really do see a variety of autonomic symptoms, but it's usually in constellation that, you know, some may be much more mild or not apparent at all, but usually when you scratch the surface, you can find subtle signs of autonomic dysfunction in patients with Parkinson's disease, even in the very early stages of the disorder. So.

Polly Dawkins:

So, if for our audience who are listening and watching, let's go through sort of what are some possibilities on that menu that might be attributed to autonomic that people, I mean, there's the obvious ones that you've mentioned the gut and the GI. And we're gonna talk about that with Dr. K next and obviously pain. Let's talk about some of the other ones that people might be experiencing.

Lucy Norcliffe-Kaufmann:

So, the one, as you mentioned, that is probably is the most common is constipation, right? So early society can also be a problem for patients. The one that tends to be what we see patients with Parkinson's disease in the autonomic clinic for are falls in blood pressure when standing. It doesn't affect every patient with Parkinson's disease. And it affects around, we estimate 40% of patients with Parkinson's disease to varying degrees. And what tends to happen is it might get a little bit worse as people age with Parkinson's disease. So, we start to see the prevalence go up, but what is happening here is because the autonomic nervous system is so critically important in controlling blood vessels in the heart when we stand up, when they're not working, patient's blood pressure falls to very low levels.

So, they don't get enough blood back to their head when they're upright, like gravity is working against them. So, what happens is people may feel dizziness, like heaviness, this vague feeling of fatigue, weakness, like they want to sit down. They might notice that their vision is a little blurry or their thinking is not as sharp. You know, it can be very subtle and that can be a sign that blood pressure is falling a little bit. And usually when it starts to fall quite low, and it varies like how low, it varies from patient to patient, people will usually start to have the urge to feel like they're going to faint, right. And sit down. So that's the most dramatic one we see patients

in clinic for. We also hear patients tell us, like I don't sweat anymore when I'm exercising, you know? And so, I have trouble to tolerating a hot environment, right.

You know, some because the sweat function is variably affected. So those are the typical signs and symptoms that you'll hear from a patient, not to forget also the urinary problems that the patients can have because the bladder is very highly innervated by the autonomic nervous system. So, if those nerves get affected, it can affect the emptying of the bladder. Another common problem we see in males with Parkinson's disease is erectile dysfunction and often retrograde ejaculation because the autonomic nervous system of course controls the sex function as well. So often, you know, erectile dysfunction is usually dismissed as a sign of aging. And in of itself, it's not a specific sign of Parkinson's disease, but it can indicate that those, you know, those delicate network of autonomic nerves that are controlling the blood vessels in the penis are also affected. So, it's often a constellation of symptoms, but when you're listening to people in clinic to try and figure out what's going on, you're listening for the signs of like the autonomic nervous system is underfunctioning right.

Polly Dawkins:

One of the questions we received in the last presentation about drooling, is that also a part of this autonomic system?

Lucy Norcliffe-Kaufmann:

It's, that's a difficult one to figure out, because it doesn't appear from at least the studies that I know earlier that the saliva glands are over producing saliva. It's probably the fact that people are swallowing less. Right. But, you know, so it might be a mix of both a change, a slight change in autonomic innervation of the salivary glands, but also most likely due to the lack of swallowing.

Polly Dawkins:

Interesting. And you touched on briefly on the topic of fatigue, is fatigue really related to the autonomic system or dysregulation of the autonomic system?

Lucy Norcliffe-Kaufmann:

Well, that's a great question because what fatigue is, is what we call a nonspecific symptom. So, fatigue alone doesn't mean to say your autonomic nervous system is under functioning right, but it can be along with, usually it comes with when this is a problem of the blood pressure control and blood pressure getting too low, usually it's fatigue accompanied by the feeling of lightheadedness, the feeling of like, I can't see properly. So, it's not just, I'm feeling fatigued and I don't want to stand, cause I know fatigue can also occur for other reasons in Parkinson's disease. Right. But it's certainly if it's always occurring in the upright position, if it improves when somebody sits or lies down and it's associated with other signs that the organs are not getting enough blood supply, sometimes people will describe this like coat hanger pain across the back and the neck as the back and the neck muscles get sort of not enough blood flow, it

produces like an angina type of pain of the back. So, fatigue accompanied by other signs and symptoms of neurogenic orthostatic hypertension can indicate that it's a problem with the nervous system.

Polly Dawkins:

So interesting. Let's before we move on and dig into some of the questions that people have on this let's watch a quick video if you don't mind, which is something I watched years ago with you. And it really helped me understand what blood pressure dysregulation, what happens in a person with Parkinson's. So, Jackie, if you wouldn't mind, would you put up that video for us?

{Video}

Meet Carl and his wife, Nancy. Carl has a condition called neurogenic orthostatic hypotension or NOH. Neurogenic means associated with the nervous system. Orthostatic means related to standing up and hypotension is abnormally, low blood pressure. For Carl, having symptomatic NOH may make him feel dizzy and or lightheaded after he stands. To understand NOH, let's take a look at the differences at what happens inside Nancy and Carl's bodies when they stand. When Nancy gets up from sitting on the couch, gravity pulls her blood towards the lower part of her body away from her brain and heart and her blood pressure lowers slightly. In response, Nancy's body naturally takes action. Her nervous system releases more of a chemical norepinephrine to help raise her blood pressure. This serves to get the blood back into the upper parts of her body. Norepinephrine sends signals to Nancy's blood vessels, telling them to constrict or get narrower, which helps the blood move back up towards Nancy's heart and brain. Nancy's blood pressure then returns to a level that's normal for her.

Now let's take a look at what happens when Carl stands up. When Carl stands, gravity also pulls his blood toward the lower part of his body, just like it did with Nancy. However, in response to standing, Carl's body does not release enough norepinephrine because he has a problem with his nervous system. So, Carl's body doesn't get the signals it needs to tell the blood vessel to constrict. That's why his blood pressure stays low. As a result, Carl, may get dizzy, have blurred vision, or feel lightheaded after he stands. If you experience any of these symptoms or otherwise just don't feel right after standing, talk with your doctor and ask, could I have NOH and how can I manage my symptoms?

Polly Dawkins:

Thanks, Jackie. Hopefully for some of you, that's a helpful visual. Sometimes a visual of what's going on in the body can relate. And especially with all those symptoms that we've been talking about. Knowing this, we have some questions in the chat Lucy about how do you take your blood pressure and how do you know whether you've got a potential problem with your blood pressure or dysregulation? Can you tell us a little bit about strategies?

Lucy Norcliffe-Kaufmann:

Yeah, sure. I think that this is very powerful because it puts the ability to be able to detect problems with blood pressure in the hands of patients. Right? Because we can, what you need is a blood pressure measuring cuff, the ones that go around the arm are better than the ones that go around the wrist, usually in terms of accuracy. So, and you want to take your blood pressure in different positions, right? So, you want to lie down for around five, 10 minutes and take a couple of readings when you're lying completely flat. And then you want to stand up and take a blood pressure reading the first minute you stand. And then the third minute you stand. And usually what happens is our blood pressure is well maintained and it's the same in the lying position as it in the standing position. But when you have Parkinson's disease and sometimes a problem with the autonomic nervous system, when you stand up, you see that fall in blood pressure and sometimes blood pressure can actually be a little higher in the lying position.

So, patients may start to see a little bit of hypertension when they're lying flat, but when they stand up the blood pressure falls. And typically, when it falls by, there's a top number, there's a systolic number and a bottom number, which is the diastolic number. And typically, we're looking for a fall of 20 millimeters of mercury systolic and 10 millimeters of mercury diastolic to diagnose neurogenic orthostatic hypertension. So, that's one way of doing it. The other thing that we sometimes advise patients in clinic is that when, sometimes they get specific times when their symptoms are very bad and it can be that the blood pressure control in a person with Parkinson's disease is not completely absent. It's just a little bit impaired. So, if you add other stresses on top of that, that may unravel and reveal the orthotic hypertension, right?

So often patients will come to clinic and tell us these typical, typical stories, but we would measure their blood pressure and it would be okay. So, then what we would do is we would ask them like, go eat a very heavy carbohydrate meal. And I'm not, we're not encouraging people, you know, to provoke these kinds of episodes, but if you did have something to eat and you did feel unwell, lie down and repeat the test after right. Lie down and stand up after you've had a meal or something like that, just to see if, you know, those are the things that are really pushing your blood pressure control to their limits, where you start to reveal the orthostatic hypertension. But you know, the thing for patients to remember is that don't be a hero when you're standing up, right, trying to get low numbers, because if it's low, we'll see it's low, right?

The idea of doing these home standing blood pressure tests is not to make yourself pass out. It's just to demonstrate, you know, how long you can stand for and what are the types of changes you're seeing within the first kind of three minutes of standing. And then if anybody is feeling absolutely terrible at any point during the day and they're kind of, you know, they've got themselves safely into a seated position, take the blood pressure, like ask somebody to come and check my blood pressure at the time we have symptoms. And then, you know, if you keep a log of all these blood pressure values, and then you write when you had symptoms as well, we can start to see are the symptoms associated with lows in blood pressure. So, you know, all the, as many readings as you can give are important, but note the posture and sort of the timing, right?

Polly Dawkins:

Right. Many physicians don't seem to know about this strategy, the supine and the blood pressure. So, I think a strategy would be to go and talk with your doctor, your clinician, about taking the blood pressure this way so that you can actually determine whether you have NOH.

Lucy Norcliffe-Kaufmann:

Yeah. And most patients in clinic, their blood pressure is taken in the seated position, right. Where in the seated position, in a patient with Parkinson's disease and orthostatic hypertension is usually normal, right? So, you may ask the nurse or the physician or whoever is taking your blood pressure, do you mind taking it while I stand up? Right? And then you can do it in a safe space, and they can check for neurogenic orthostatic hypertension.

Polly Dawkins:

Got it, got it. One of the questions that's coming in from a number of folks is about back to the body temperature regulation. Can we talk a little bit about this, whether it's related to really cold hands and cold feet or sweating and excessive sweating, can you tell us a little bit about how that's all related to autonomic systems?

Lucy Norcliffe-Kaufmann:

It's not well defined how the, we don't understand the temperature regulation and sweat control in Parkinson's disease, as well as we understand the blood pressure, let me start there. Right. So, we do know that there are tiny networks of nerves that go to the blood vessels that control whether they dilate or constrict if you want to dissipate or conserve heat. So those can sometimes be affected in Parkinson's disease that makes it very hard for people to thermal regulate. Right. And then the other thing, there may be some involvement of the central areas perhaps that are involved in central, well, I'm talking in the brain right, deep in the brain that are involved in the control of temperature too. So, you know, and the circulation can, you often see people have like either dark skin or, you know, in the lower extremities as the blood is pooling.

And sometimes a very pale look in the face when somebody's standing can be an indicator that the blood pressure is very low. Usually, people develop what we call pallor whether, you know, the literal, the blood has been drained from them, right? I mean, you look, they will often look very white and pale when they're, when the blood pressure is low. Right? So, there's a lot of different temperature control issues. Sweating is variably affected. Some people usually sweat less, right. But other people may report like, oh, I sweat in particular areas. Or I you know, there can be, sweating is not so universally affected in Parkinson's disease. But the typical story you hear is that just don't sweat when I exercise. Right.

Polly Dawkins:

And then of course, body temperature gets affected if you're not sweating to

Lucy Norcliffe-Kaufmann:
Right. Right.

Polly Dawkins:
What about, one of the questions is around heart rate. So, while exercising, inability to control heart rate, or keep it at a high, get it to a higher level or keep it lower. Any thoughts on whether that's related to the similar systems?

Lucy Norcliffe-Kaufmann:
The heart rate in Parkinson's disease is particularly fascinating because it's probably one of the first things we start to see affected. If you look at big cohort studies of what we call premotor Parkinson's disease, right? There are signs that there are two nerves, two autonomic nerves, two branches, right that go to the heart. One is the parasympathetic nerve, the vagus nerve, which slows down the heart. And the other one is the sympathetic nerve that speeds up the heart, right just to put simplistically. Very early on in these premotor cohorts of Parkinson's disease patient, you see that the fluctuations by the vagus nerve are affected super early on, you know, even before the motor signs and symptoms, but that doesn't necessarily have symptoms associated with it. There are other studies that show in the premotor stages, also that exercise, maximal heart rate when exercising in somebody with, you know, premotor Parkinson's disease can be less. So those nerves that are speeding up the heart and making the heartbeat faster are also affected by the same protein accumulation process. So, they get, the heart sort of gets, the nerves get filled with alpha-synuclein. So, you start to see that heart rate won't go up as much. And also that the fluctuations that are induced by breathing aren't as much as a, when the nerves are functioning. Right. So.

Polly Dawkins:
Interesting. All right. One of the things you and I talked about before this is let's about strategies. You know, it's really important to know about all of this, but what are some strategies specifically non-pharmacological strategies that individuals can take if they're experiencing these symptoms, where do you think a good place to start to talk about strategies would be?

Lucy Norcliffe-Kaufmann:
Well, I think the most, the first place we talked about it was of course, measuring the blood pressure, right. And understanding those changes. And the first thing we always start with when we diagnose a patient with orthostatic hypertension is telling them about the effects of posture and gravity on blood pressure. Right? So, as we saw in the video, you're lying flat, your blood pressure is normal. You stand, you sit up, it's okay. You stand up and it falls to low levels. So, to understand the effects of gravity on blood pressure, I think is the cornerstone for anybody to manage their symptoms. And we always tell patients in clinic, like, don't be a hero, right? If you're feeling your blood pressure is low, sit down, right. It's better that people sit

down, than fall down. Right? So, and what we teach them are these physical counter maneuvers.

So if you tense the muscles of the thighs, the muscles of the buttocks and the abdomen, like really, really tight, you can actually force blood back to your heart. So, you're helping maintain the blood pressure and those like simple tensing releasing tensing releasing you can pump the fists also that helps you buy a little bit of time and increase your blood pressure until you can get to a seated position. If blood pressure is extremely low and somebody's still feeling bad, you can raise the legs a little bit, often that helps to bring it back up kind of quickly. So, the first thing is to understand posture. The next thing is really fluid and water, salt and water, right? I mean, we advise people that they should drink between, you know, two and two and a half liters of water a day, because you know, the water helps expand the amount of volume you have inside your body.

Right? So, remember that the blood pressure is mainly the blood vessels squeezing. So, if they're filled with fluid, they're going to squeeze at a higher pressure, right. Whereas if you're dehydrated and you don't have a lot of force to squeeze around your blood pressure is lower. So, we teach people to maintain good hydration, to be aware that, you know, it's fine to have a cup of tea, coffee, or even a glass of wine, but keep in mind that will get you dehydrated. So, you should always be replacing fluids. And we tell people that, you know, if they're going to have a glass of wine or something like that, do it in bed, like do it in the seated position. Like make sure you're not getting up after you know, avoiding all those triggers. So, and then small carbohydrate meals, like when you eat a big carbohydrate meal, like after sometimes lunchtime, you feel like a little sluggish. If you've had like a big bowl of pasta or something like that.

In somebody with Parkinson's disease, it can actually cause the blood pressure to go quite low. And that's often a time when patients say my NOH is at its worse and that's because the blood is diverted to the guts to aid digestion so it's not in the rest of the circulation where you need it and it's not getting back up to the heart. So, we always advise people like low carbohydrate meals, like eat more frequently during the day instead of, you know, loading a big carbohydrate meal at front. So, you know, those are the basic lifestyle changes that we usually have patients make. And if the OH is not so severe, some patients can get away with just the nonpharmacological lifestyle changes that we have. Others may need to go a little bit further, right? Sometimes we recommend sleeping with the head of the bed upright. So, you sleep on an angle. We may recommend compression stockings, or particularly, you know, the ones that come waist high are the ones that are most effective or an abdominal binder, because, you know, putting pressure on these areas prevents the blood from dropping there. Right when you stand up. So.

Polly Dawkins:

Is an abdominal binder, like a girdle?

Lucy Norcliffe-Kaufmann:
Yeah.

Polly Dawkins:
That's still something you can purchase?

Lucy Norcliffe-Kaufmann:
Yes. Yeah. There are abdominal binders. They're not necessarily like so comfortable, but some patients find if they're upright and they wanna go for a walk or do something like that, they can be quite helpful.

Polly Dawkins:
You mentioned some of the changes to diet including increasing fluids, you touched on salt, but what, tell us a little bit more about salt.

Lucy Norcliffe-Kaufmann:
Yeah. So, you need, we spoke about trying to keep that volume inside of you, right? So, one thing you need to keep volume inside of you is water and salt. So, you need the salt to hold onto the water. So, we typically recommend that patients take like one to two teaspoons of salt per day. Right. But again, you know, these are some things that you should definitely discuss with your doctor because there's a lot of controversy around salt and high blood pressure. Right. You know, those are things that people can do, but they should be done very carefully with a physician to make sure that they're not raising the blood pressure too high, but typically extra salt, extra water can help. And then one thing that is really kind of fascinating is that if you drink like a pint of water, like 500 milliliters of water, that in the patient with Parkinson's disease can cause the blood pressure to go up quite a bit. Right. So, loading with a big pint of water is often a very good way to raise the blood pressure. It starts to work after about 15 minutes and lasts for around 30 minutes, but you can get a very strong blood pressure increase with just, you know, one big glass of water.

Polly Dawkins:
So, the other side of that coin, somebody's asking, but then I have to urinate all of the time. And if I'm having incontinence issues or any strategies there, just ensure you're next to the restroom all the time?

Lucy Norcliffe-Kaufmann:
Yeah. We, it's so difficult. It's, that's really because the water is quite effective. But as you say, like if you load with, if you drink a pint of water, it's gotta go somewhere. Right. So, the tricky part is like when to do this right. And to be aware that, you know, you may need to, to go to the bathroom. Right. But you know, it's a payoff because we know that maintaining, if a patient has neurogenic orthostatic hypertension, maintaining volume status is critical, right? So, it's just

finding that balance and knowing that, you know, the water intake should be as much as you can tolerate without driving yourself crazy and needing to go to the bathroom. One of the common problems we hear is that patients need to urinate a lot at night. This is because when they're lying flat in bed, the pressure can be slightly high.

Right. And then that's causing the kidneys to filter more. And the kidneys are excreting, a lot of water, which is why people may need to get up sometimes several times a night to use the bathroom. We had patients in the past tell us like, I don't know why I just don't sleep in the bathroom. So, one, you know, of course it can be devastating. It can really impact your sleep. And we take it very seriously. Like what we try and do is we give people in the clinic, we like to measure their blood pressure at night to make sure that it's not on the high side. And if it is on the high side, we encourage people to raise the head of the bed so that they're sleeping, like at an angle with a gravitational force all night, and that can lower their blood pressure a little bit and stop the kidneys having to filter as much at night and stop people having to get up as much at night to use the bathroom. Right. So that can be something that it doesn't always completely solve the problem, but it can help people a lot, you know, reduce the number of trips to the bathroom when they're sleeping. Right.

Polly Dawkins:

Okay. That's interesting. One of the things we haven't talked about Lucy in terms of strategies is exercise. Is there a suggestion that you have about exercise and which exercises that might help with some of these autonomic symptoms?

Lucy Norcliffe-Kaufmann:

That's, we always encourage people to stay as active as possible because part of the problem of having insufficiency, problems with the autonomic nervous system, right, particularly problems with blood pressure is that people cannot feel like standing, right. If every time they get up, they don't feel like they feel dizzy, like they want to sit down, it can lead to this like vicious cycle where people are not moving. And one of the critical things you have to be able to control your blood pressure is those muscle pumps we spoke about, right? The tensing the buttocks, and the thighs to keep the blood moving. So, you need the muscles to be strong, right? So, any form of strength training, exercise for the abdomen and for the, you know, for the buttocks and the thighs, those kinds of areas can be very, very helpful.

The other thing that we recommend is to adapt exercises. So, you're not performing an exercise in the upright position, because if you add the stress of exercise on top of the stress of like your autonomic nervous system not working as well as it should do, you can push it to the tipping point. Right. So, and the idea is not to make yourself pass out. So, we recommend if people are gonna exercise to use like a reclining bike. So, they're exercising, but they're not having so much of a gravitational stress. Another thing that's excellent is exercising in a pool, cause you have the hydrostatic effects of the water that sort of holds your blood pressure up. You need to

keep the head upright, right? But you know, that can be very effective in maintaining blood pressure while somebody's moving in an upright position.

Lucy Norcliffe-Kaufmann:

A good PT, a good physical therapist and somebody that can help develop an adapted exercise plan is the key for many, many patients that remain as active as they can for as long as possible. Right. So.

Polly Dawkins:

Yeah. Yeah. Great. I'm gonna turn to my other screen and look at some of the questions. I guess there's one thing before I look at those questions, you had also touched that sexual dysfunction, erectile dysfunction, I want to mention that we will be having a webinar in April that's gonna be focusing on men and Parkinson's, so we're gonna have some urologists and others join us. So, we'll be able to really dive deep into some of those topics, but before we do that, one of the questions is that can women experience sexual dysfunction because of autonomic nervous system disorder?

Lucy Norcliffe-Kaufmann:

Yes, yes. That can manifest of course in different ways. Right. Some women report dryness or discomfort when having sex. Right. So definitely can, I think we probably know less about female sexual dysfunction related to problems with the autonomic nervous system than we do in males, but there's a lot of literature linking, you know, the autonomic nervous system, like the vagus nerve, you remember there were two, like the ying and yang, the sympathetic that amps you up and the vagus that calms you down. I saw recently publications linking the vagus nerve to female orgasm. Right? So, it's likely that, you know, if we delve deeper and we understand it further, the involvement of the autonomic nervous system does lead to sexual dysfunction in women also with Parkinson's

Polly Dawkins:

Interesting. One of the questions about sexual dysfunction in men, somebody mentioned taking Viagra or a medication to help with erectile dysfunction. Tell us a little bit about the effects on the autonomic system if that medication is taken.

Lucy Norcliffe-Kaufmann:

Well, that's a great question to bring up because Viagra is what we call a vasodilator. So, it's something that widens blood pressure, blood vessels, and in the way that it widens blood vessels to the penis to allow an erection, it can also widen blood vessels in other areas of the body. So that can cause blood pressure to drop very low. Right. So, we can, we often hear for patients with Parkinson's disease or early on in the disease process will tell us, I took Viagra and then I fainted. Right. So, you know, be very careful with Viagra. If we always advise people, if they're gonna take Viagra, have sex lying down, right. I mean, don't introduce the Viagra and orthostatic stress and exercise, right? So, Viagra is, we have to be very careful with those kinds of drugs because they can lower blood pressure quite considerably and they can make patients

feel very tired or groggy the day after. And they can linger a little bit. So people will often describe the next day. They might feel a little bit weak. So, you know, it's just something to keep an eye on and keep in the back of your mind and discuss it with your doctor, but certainly, you know, take a lot of precautions after taking Viagra.

Polly Dawkins:

Got it. Thank you for addressing that. All right. Well, we've got about oh eight minutes here to answer about a hundred questions. Many of them we've already covered. Is there anything we spoke earlier with Dr. Fleisher about pain, any connection between pain and the autonomic system?

Lucy Norcliffe-Kaufmann:

They're very connected, they're very connected. You know, this pain can activate autonomic outflow to the body quite dramatically right. Now, whether or not that connection is still working in Parkinson's disease will depend on how severely the blood pressure control mechanisms in particular are affected. Right? So, there is a connection, but it may be quite variable.

Polly Dawkins:

Got it, got it. As with many things with Parkinson's. Yeah. A number of questions are being asked about eyes and eye movement. And you mentioned blurriness and vision. Is there any linkage between eye movement or anything going on in the eyes besides, or in addition to blurriness that's related to the autonomic nervous system?

Lucy Norcliffe-Kaufmann:

So, the eye movements is part of motor control, right? So that's not the autonomic nervous system. What is the autonomic nervous system is the dry eye that sometimes patients experience, right? So, they may find that they need to use eye drops because the pupils get, you know, very dry. This can be particularly problematic if somebody, for example, is using assisted ventilation at night also. So, we recommend like eye ointments, you know, to prevent the eyes from getting too dry. So, and then you of course have vision difficulties that occur with, like, you're not getting enough blood to the retina, right. So, you know, and probably the lobes in the brain that are responsible for interpreting the visual signals. So, you have multiple effects of the eye, right, from different angles, but some of those components are a problem with the autonomic nervous system.

Polly Dawkins:

That's so complicated.

Lucy Norcliffe-Kaufmann:

Indeed.

Polly Dawkins:

All right. I'm going to, so many questions about blood pressure, but I think we've really answered many questions. If somebody out there feels that their blood pressure question wasn't answered, please put it back into the chat. Back to the eye question, somebody's talking about, is it a difficulty in detecting low light, anything related there?

Lucy Norcliffe-Kaufmann:

So, there's a pupil accommodation that occurs with light and some patients will report, you know, there's difficulty, they have difficulty there, right? So again, you know, I think the eye for being such a small organ is so complicated, right? And there's a number of different nerves that function within the eye to control the eyes abilities, right? So, you definitely, you know, those problems with the pupil accommodating to light can also be part of Parkinson's disease.

Polly Dawkins:

Got it. Any strategies that you know of, or could recommend for folks who have as you've said drops for dry eyes, or eye ointment, any other strategies on eye issues that are related to it?

Lucy Norcliffe-Kaufmann:

Some of our patients have told us that they are more comfortable with sunglasses in very bright lights. You know, that's, I mean, I think there's so much that comes from listening to what, you know, other people going through have found the solutions are helpful, but some people say sunglasses.

Polly Dawkins:

Got it. And we're getting a few more questions about blood pressure about what if you have just high blood pressure and not the NOH, are those related to Parkinson's the high blood pressure and has that been studied and high blood pressure related to ON and OFF periods, are those related?

Lucy Norcliffe-Kaufmann:

High blood pressure in and of itself can occur in anybody with Parkinson's disease, like the garden variety hypertension, right. I mean, it can. It can also be, as we spoke about high in the lying position and low in the standing position. So, and typically if blood pressure is fixed and high all the time, that's not neurogenic orthostatic hypertension, right? That's regular hypertension. And that's something, you know, to discuss with the doctor and see a cardiologist. If it's fluctuating a lot with ON/OFF times, when standing up, after eating meals, that can indicate that there is a problem with the autonomic nervous system. And that's again, something to bring forward to the doctor. And I think that's where we come back full circle to this idea of like, take the blood pressure, write it down, let us know what the fluctuations are, so that when you go into the doctor, the doctor is seeing you and taking your blood pressure in the seated position and standing up if you ask, right, but you are coming in with so much of a wealth of information saying, this is how my blood pressure behaves over a day over a week

over, you know, and that information provides a big picture that the clinician can then interpret and figure out whether there's a problem with blood pressure control.

And if there is how best to treat it, because the treatment of regular hypertension is different from the treatment of neurogenic orthostatic hypertension. Right. So.

Polly Dawkins:

Right, right. We have time for about one more question and I'm going through a few of them here. Sorry about that. Some of them, I don't really understand, I'm sorry, folks. There are so many still around the urinary issues and autonomic, I'm not quite sure, you've addressed that they are related, do you have any other comments on urinary issues with autonomic issues that we haven't addressed?

Lucy Norcliffe-Kaufmann:

Yeah. I mean, I think there are different aspects of urinary dysfunction in Parkinson's disease. There's those that are primary that, you know, the nerves of the bladder are affected. But they will typically manifest, like a lot of patients will tell you they have urgency or the feeling that they haven't completely emptied their bladder, or they need to go again soon after they're emptying it. That can be a sign that there is like a problem with the nerves controlling the bladder. Another thing that we see in extreme cases is a lot of urinary tract infections, right? Because if you're not emptying the bladder, the urine can accumulate bacteria and you can start to develop a urinary tract infection. Right. And those are big things to watch out for. Right. Then there are the effects on the bladder of secondary to the autonomic to the blood pressure being out of line.

Right. So, you may have, you know, like we spoke about, this urgency at night, this frequency at night to keep getting up. Right. So, you know, it's really, the bladder is a complex issue in Parkinson's disease. We used to think that there wasn't so much urinary bladder dysfunction in Parkinson's disease, and that was more of another kind of disease, but now we're increasingly recognizing that some patients with Parkinson's disease can have really severe bladder issues. Right. There are drugs available. Like I know we're talking about nonpharmacological things here, but there are a number of different options that people can try for the bladder issue. The danger is like if they're using the common one is an alpha blocker, right, like Flomax that a lot of people are given when, you know, they assume that there's a problem with the prostate for men, and that can actually lower blood pressure quite a lot. So, if you do try something for the urinary bladder issues that you might have, like, just be aware that, you know, just to keep an eye out that this doesn't worsen your blood pressure control, for example.

Polly Dawkins:

Got it. Wow. This time has gone by so quickly. We could speak for another 45 minutes about all of the questions folks have. Thank you for the work that you do in this area. And for the really easy, simple explanations you've given to our really complicated topic.



Lucy Norcliffe-Kaufmann:
Thank you for having me.

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