

Michael J. Fox: This is Michael J. Fox. Thanks for listening to this podcast. Learn more about The Michael J. Fox Foundation's work and how you can help speed a cure at MichaelJFox.org.

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.

Larry Gifford: Thank you, everyone, for joining us. I'm Larry Gifford and I will be your moderator today. I was diagnosed with Parkinson's disease in 2017 at the age of 45. I sit on The Michael J. Fox Foundation's Patient Council, and I host the podcast When Life Gives You Parkinson's, which you can find linked in the resource list on your screen.

Larry Gifford: Today we're going to discuss a few things, how Parkinson's can impact your sex life, sexual changes women can experience, sexual changes men can experience, how medications can impact sex drive, how to treat sexual dysfunction with Parkinson's. Let's meet our panelists for today's discussion. With me today is Dr. Camille Vaughan, an Associate Professor and Section Chief of Geriatrics and Gerontology at Emory University in Atlanta, Georgia. Thank you for being here, Dr. Vaughan.

Dr. Camille Vau...: Thanks so much for the invitation.

Larry Gifford: Dr. Daniela Wittmann is an Associate Professor of Urology at the University of Michigan, and a certified sex therapist. We're glad you're with us too, Dr. Wittmann.

Dr. Daniela Wit...: It's a pleasure to be here. Thank you.

Larry Gifford: I want to start with something that may make us all just take a deep breath and relax. We are all in this sexual adventure together. The headline of this slide alone makes me feel better about myself, sexual challenges are common with people with Parkinson's. Whew, I'm not an oddball. Some studies suggest as many as 70 to 80% of people with PD experience some aspects of sexual dysfunction. Does that line up with your experience Camille?

Dr. Camille Vau...: Yes. We actually often have people bring this up to our attention if we've kind of created the environment to make it easy to talk about. A lot of people do report complaints and there are often things that we can do to help.

Larry Gifford: There was a Fox Insight study, and 35% of the participants with Parkinson's said they found it difficult to have sex within the last month. Dr. Wittmann, does that line up with your experience? Because for me that seems like a low number.

Dr. Daniela Wit...: Well, I would say that it is a more prevalent situation than perhaps this slide suggests. It just depends on how people really answer these questions and how comfortable they are answering this. I meet largely with support groups of people with Parkinson's. Those are always very, very, very well-attended groups, suggesting that it's really quite a big problem for people. That's why we think of it as sort of a normal problem in Parkinson's.

Larry Gifford: Yeah. I think the thing that catches people off guard here is sex within the last month, because a lot of us, me included, are thinking, "Have I had sex in the last year?" The last month just seems too aggressive.

Dr. Daniela Wit...: That makes a lot of sense.

Larry Gifford: Yeah. Then 35% of the participants with Parkinson's said they take medication for sexual dysfunction. We'll get into some of those medications and treatments throughout the day. Then aging, hormonal changes and some medications also can lead to worsened sexual changes. Let's talk a little bit about some of the Parkinson's symptoms and effects that can change your relationship. Dr. Wittmann, we'll start with you in talking about some of the motor symptoms. Can you walk us through some of the points on this slide?

Dr. Daniela Wit...: Yes. When people start losing some control over how they move their bodies, not only is there sort of the physical difficulty of moving through a sexual situation, but it can really also affect confidence about accomplishing sort of the sexual emotions that people feel that they can proceed with. In many cases, in our research we have found that sex tends to be very nonverbal for most people throughout their life. All of a sudden, there really needs to be more of a need to talk about what's going on and accommodate. It can make intimacy difficult.

Larry Gifford: My wife and I have talked on the podcast about how, because I have stiffness and slowness and tremors, she's sometimes, because of my motor symptoms, she's afraid to touch me because she's not sure how it's going to affect me.

Dr. Daniela Wit...: Yes. That of course, again, sort of highlights the idea that it's so important to talk. It sounds like you guys talk. People need to be able to feel comfortable because it interrupts the flow of arousal as well when there's a concern that the person with Parkinson's is uncomfortable or that they would be affected negatively.

Larry Gifford: Then Dr. Vaughan, some of the facial masking and speech difficulties can impact how you show and share your affection, but there's also sleep changes. Can you talk about some of the sleep issues that people might have that can also impact intimacy and sex drive?

Dr. Camille Vau...: Yeah, absolutely. I mean, I think that there may have, in a time when someone didn't live with Parkinson's, there might've been traditional kind of times that they engaged in sexual activity with their partner. It might've been in the

evening or at night. As someone's living with Parkinson's, that might not actually be the best time for them anymore. We'll kind of get into some of those strategies [inaudible 00:06:13]. Thinking about kind of what is the best time of day when you're the most awake, alert, when your motor function's the best, is one thing to kind of keep in mind in kind of thinking about timing of engaging in kind of intimate activities.

Dr. Camille Vau...: Same thing, some people may have more sleepiness during the day as well, and so kind of looking at kind of your patterns and what are the best kind of windows of time. You may have to kind of create an environment to promote kind of that intimate behavior, even if it's in a time of day that maybe wasn't traditionally when you and your partner were thinking about having sex. Maybe that's making the room darker and kind of thinking about it, trying to get blackout curtains, or having kind of the bedtime routine in place, even if it's in the middle of the afternoon, because that's maybe the better time for you.

Larry Gifford: Yeah. Light some candles, put some aromatherapy around.

Dr. Camille Vau...: Exactly.

Larry Gifford: Make it your little romantic oasis. Planning, my wife and I, we met with a sex therapist and she's like, "Listen, all your life you've actually planned your sexual encounters. You made a date on Tuesday for Friday night, so you spent the whole week priming and prepping for that night, knowing that you're probably going to have sex." We never wanted to think of it like we were planning when we were going to have sex. Now it's we just need to be more open to ourselves and truthful to ourselves about, yeah, we need to plan this because spontaneity doesn't really work.

Dr. Camille Vau...: I think you're exactly right. Exactly. I think you're exactly right, that even when we think about times maybe when Parkinson's wasn't part of the mix, we really were kind of planning out those times, got into routines, and we just have to kind of readjust in the setting of Parkinson's. Exactly right.

Larry Gifford: Dr. Wittmann, the impact of Parkinson's on body image, can you talk about that a bit?

Dr. Daniela Wit...: Yes. I think anytime that we have any physical changes that suddenly we have less control over our bodies, our sort of sense of ourselves and the confidence in ourselves begins to erode because we now can't predict how we're going to feel and function from moment to moment. When it comes to making love, there are two issues. One is how am I going to function myself, but also what kind of pleasure am I going to be able to provide to my partner? There's just a lot of sort of concerns that sort of in Parkinson's affects the body that begins to rise in importance. How confident do I feel that I can manage my body well, and how well can I be for my partner?

Dr. Daniela Wit...: Obviously that's a very strong emotional impact. Once we start worrying and thinking about how are we going to do, again, it sort of takes away from the arousal. There's got to be a lot of reassurance that has to go on mutually, and willingness to be honest and open about what's going on. I think that makes it much, much more manageable when there's a person with Parkinson's can be reassured that their partner still feels loved by them, still feels attracted to them, still feels that they can have pleasure in the relationship. In both direction it's an issue, and reassurance plays a very, very strong part.

Larry Gifford: Dr. Wittmann, before we move on, can you help us define what we mean when we talk about sex? What is the ... Is it just intercourse or is there more to it?

Dr. Daniela Wit...: Yes. I'm extremely thrilled that you asked me this question because it really is a very, very broad area. Parkinson's affects people from perhaps ages in their 40s and up, but a lot of older people are affected by it. By the time that people get older, oftentimes they're very reliant on intercourse and think of intercourse as sex, when in fact, sex is a lot of different things. Sex is a sensual touch. Sex is masturbation. Sex is giving and getting oral sex. Sex is using vibrators for stimulation. There are all different kinds of ways that one can be sexually active, if one's single, with oneself, or if one's partnered, with one's partner. I think what's very important for anyone with Parkinson's disease is to be open to expanding that repertoire. We probably all had that repertoire when we were 16 and weren't allowed to have sex. Everybody kind of went in every direction they could, but as people get partnered, their sex life can become a little bit more narrow and suddenly intercourse becomes the only thing. It is not the only thing. I'm really glad you asked me that question.

Larry Gifford: Great. We're going to move on to the next slide. This is about sexual changes women have with Parkinson's. I'm going to stick with you Dr. Wittmann, and then when we get to the men I'll get to you Dr. Vaughan, but if you have something to add here, feel free to chime in. Can you walk us through this slide, Daniela?

Dr. Daniela Wit...: Yes. Let me say that when we talk about Parkinson's, we also have to factor into it that some of the women who are diagnosed with Parkinson's may already be menopausal or post-menopausal, which means that there will be a loss of estrogen in the body, which lowers libido and interest in sex and which causes vaginal dryness. There could be pain with intercourse. There may be already some challenges to climax, although usually the stimulation of the clitoris can still be quite viable for orgasm.

Dr. Daniela Wit...: Now with Parkinson's, when there is the decrease in dopamine, it has some of the same effects. There can be loss of sex drive and then insufficient lubrication, inability to achieve climax. Some of that also depends on where the Parkinson's is affecting the nerves, to see whether there's vaginal lubrication and comfort with intercourse. Yes. Intercourse can become painful. Then it's very important to talk with one's gynecologist or one's neurologist about what are some of the remedies for that. There are remedies. There are lubricants and moisturizers

that can be used. Again, vibrators are very, very good for stimulating blood flow, particularly for example, in the clitoral area that helps with sexual sensations. Even though some people tend to think of vibrators as some kind of strange, foreign, fake penises, they're basically just stimulators of blood flow, which is very, very useful for producing sexual stimulation. Yes, all the things that you see on the slide can happen. It's important to recognize that these things can be remedied and discussed with one's doctor and systematically work towards improving them.

Larry Gifford: Well, you say it can be discussed with your doctor. I know every time I go to the urologist, they ask me on a questionnaire about my sex life, but then it's never discussed in the session. Is that my responsibility to bring it up to him or ... It's kind of an awkward thing to bring up. If you're embarrassed, how do you get your doctor to address it? Do you have some tips for folks?

Dr. Daniela Wit...: Yes, I do. In fact, any support group that I've ever gone to, people always really want their doctor to start the conversation, because they're not sure whether it should be part of their like neurological care, or they're just embarrassed. It's ideally the doctor who should bring it up, but we also know that often doctors don't, just as Larry is saying. First of all, you have some tips on a sheet that's available sort of as a part of this webinar, but I think it's important to recognize that this is a concern. Then I think perhaps sit down and think about what the concern is and write it down. I think sometimes it helps to leave a message for the doctor that you want to discuss sexual concerns ahead of time so that the doctor can, A, address your questions, but also in some cases inform himself or herself about the sexual side effects of Parkinson's and how to remedy them, or who are the specialists that the doctor can refer you to so that you can actually get the help that you need.

Larry Gifford: Right. I mean, they may refer you to a urologist to check you out, to see what kind of medication you may need.

Dr. Daniela Wit...: Yes, they could send you to a urologist, the woman can be sent to a gynecologist, but remember that those conversations are not always easy in those offices either.

Larry Gifford: Right.

Dr. Daniela Wit...: I think it requires persistence until you get the right person. Sometimes that person that is a mental health provider with training in sexual health. In urology, there's a specialty, sexual medicine specialty, and those people are much more likely to have that conversation with you than just a general urologist.

Larry Gifford: We are getting some questions about if sex or masturbation can be helpful to Parkinson's disease by releasing extra dopamine, to either of you.

Dr. Camille Vau...: I don't think that we have any evidence necessarily of the kind of potential for it to help with this, releasing dopamine, at least not in some sort of longterm way. I would say that sometimes for some of the lubrication issues, that having more sex will help with kind of lubrication, at least that's our experience with women. I do think that sexual health is a really important part of our overall health. I think regular sexual activity is an important part of overall wellbeing. Regardless of whether it has a specific effect on the Parkinson's disease process itself, I think it's a really important part of overall health in general.

Dr. Daniela Wit...: I did want to second that, if I may?

Larry Gifford: Sure.

Dr. Daniela Wit...: I really want to second that, because sort of classically when we talk about sexual function, we talk about the fact that a sexual stimulation gives a rise to dopamine in the brain. I don't really know how it is different in the brain of a person with Parkinson's, but we all know that sexual stimulation, heavy orgasms, kind of adds to one's sense of wellbeing, or can. To the degree that it's pleasurable and that it's pleasant, it can't be anything but something positive.

Larry Gifford: Well, that's an important point. I think that we can't stress that enough. I'll ask you each to answer this. How important is it for people to have a healthy sex life?

Dr. Camille Vau...: I think that it's also driven by the individual and what their own goals are for their sex life, but I think for many people it's just as important as your regular exercise routine and those healthy relationships in your life that help with stress management and your ... I consider it a really important part, again, of someone's overall wellbeing, but the frequency of the activity might vary depending on the individual's kind of goals for themselves, and interest as well. There certainly can be an aspect of anything that's good in our life of also too much or kind of behaviors that can be troublesome for relationships. We should also kind of keep that in mind is how is one's sexual health impacting their overall relationships with other people too.

Dr. Daniela Wit...: Again, I quite agree with Dr. Vaughan. I think everybody sort of has to look at their own situation and see what's available to have a healthy sex life. I think a healthy sex life for a single person can be just masturbation. A healthy sex life for somebody who's feeling already quite handicapped by Parkinson's can be infrequent but loving sexual contact and affection. I think we have to think about definitions and what's available. That's one part of it, but I want to tell you a story. Here in Michigan, at Wayne State University, they responded to some research findings that sexual health, frequency of sexual activity or being sexually active was associated with better physical health. They took it to nursing homes and they studied, compared to people who were sexually active with people who were not, and found that people who were sexually active had a much better sense of wellbeing and were less depressed. They couldn't really

establish the physical health necessarily, but there was something about being sexually active that seemed to have a positive effect.

PART 1 OF 3 ENDS [00:20:04]

- Dr. Daniela Wit...: Being sexually active that seemed to have a positive effect on much older people.
- Larry Gifford: I think one of the fun parts of a sexual relationship with somebody is the flirtation, the lead up to it, the intimacy, a text from work or a handwritten note in their lunch. That sort of the build up to that event could also be exhilarating and fun.
- Dr. Camille Vau...: 100% totally agree.
- Dr. Daniela Wit...: Absolutely.
- Larry Gifford: All right, so let's move on to some sexual changes with men and Dr. Vaughn, I'm going to have you lead us through this conversation. We are getting a lot of questions around this. Why don't you go ahead and start talking about what some of the sexual changes we can expect in men? Then we've got some questions from the audience that we'll pepper you with.
- Dr. Camille Vau...: Okay. So I think because of some of the ... and again, while dopamine is the kind of neurotransmitter that we focus on a lot in Parkinson's because of the treatments that we have that often are focused on dopamine as well, there are various parts of the nervous system that are involved in sexual performance that also are involved. Maybe, impacted in Parkinson's that are part of the dopamine system, but maybe part of other systems as well that involve other, like the sympathetic and parasympathetic nervous system that lead to some of these effects that you're seeing on this slide. And so, it is often a multi-kind of factorial condition. In addition to that, just the impact of Parkinson's. You may also have have other medical conditions if the person is living with and other medications that a man may be on that can impact sexual function.
- Dr. Camille Vau...: Just keep in mind that even if we're talking about some of the changes that we are connected to, living with Parkinson's and the impact of Parkinson's on the body, that there's often several factors that are impacting sexual function, which gives us more opportunities again, just to look at different treatment options. As in women, there may be decreased libido or sex drive is the setting of Parkinson's with the loss of dopamine. Now, some of the medications that are used for Parkinson's may actually lead to some hypersexuality. But generally, what we think of as being related to the disease process in Parkinson's leads to decreased libido. There may be some difficulty in attaining an erection or in maintaining an erection that's sufficient for intercourse. And so that's where we have several different treatment options that are available to

help with erectile function in men, which gives us again, support drug therapy options in men that are not always available for women living with Parkinson's.

Dr. Camille Vau...: In the setting of ejaculation, you could have experienced delayed ejaculation or too early. There are also some medications that are often used in the setting of prostate enlargement in men that may lead to something called retrograde ejaculation. And so, if there are ejaculatory concerns, then those are also something to bring up with your doctor to see if there are medications that might be impacting that as well.

Larry Gifford: To what you were just talking about, I just went to the urologist last month for some incontinence issues. They gave me Flomax and they told me that that would happen with Flomax, and that one of the side effects was the retrograde ejaculation.

Dr. Camille Vau...: Yeah. I will say that there's nothing really dangerous or problematic necessarily about not having an ejaculation or having the retrograde ejaculation. It just may be a very different experience than what someone has experienced prior to that time, and so letting them know to expect that. I'm glad to hear that you were warned about that ahead of time, too.

Larry Gifford: Well, and what's interesting is with everything with Parkinson's, it's a new experience. Every day is a new experience. Why should this be any different?

Dr. Camille Vau...: Yeah, it's good to bring up things so that people may not have associated with Parkinson's or realize that this is a potential condition that occurs also. So that if there are treatments available, those are being brought up to your healthcare team, and we often do have things that we can do to help.

Larry Gifford: Does levodopa cause erectile dysfunction?

Dr. Camille Vau...: Levodopa can impact, I will say, blood pressure from some people who, as they're on increasing doses of levadopa, may experience more low blood pressure. And to the extent that having low blood pressure and could impact the ability of the penis to the veins and the penis to kind of engorge and fill, which is one of the important steps and leading to an erection, I think that's a possibility. As far as levodopa itself causing other challenges though, we don't commonly think of that as the main side effect of it. And to the extent that levodopa would help someone move better, it might be that those things would kind of balance each other out and the potential that you have better mobility, which could allow you to engage in activity more easily. I'd say that in general, probably having levadopa onboard is more helpful than potentially causing a side effect that would limit sexual activity. But certainly, if you're experiencing a lot of low blood pressure with it, we want to bring that up.

Larry Gifford: There is a question here about managing or minimizing tremor while getting anxious or excited, which can worsen the tremor with sex.

Dr. Camille Vau...: Yeah, I think if you know that it's there ... I mean you might think about what are the best times with your medication effect from the medications that those dopaminergic medications. So whether that's [inaudible 00:26:10] or one of the dopamine agonists, it's usually around 45 to 90 minutes for those medications to have kind of peak effect. Everyone's a little different. And so thinking about the timing of intercourse or sexual activity, intimacy with best function or best on time with your medication, dosing's priority important. Exactly right. If there is excitement, anxiety, that does sometimes bring on more tremor activity. I might suggest that to maybe engage in a sexual activity or more frequently, and that may help with that over time. I think then having that conversation with your partner about what you're experiencing as someone living with Parkinson's, and that let's move on forward through that as we can are things to consider as well.

Larry Gifford: Yeah. And maybe maybe that's not the day you have intercourse. Maybe that's a day where you do something different.

Dr. Camille Vau...: Mm-hmm (affirmative).

Larry Gifford: We have a couple of comments here on how to date with Parkinson's and navigate sex with somebody new. I'll start with you Dr. Vaughn, and then I'll give Dr. Whitman a chance to chime in as well, because I think this is an important topic.

Dr. Camille Vau...: Yeah, I think I saw a question kind of in preparing for the webinar also on this topic kind of when to disclose. And I think that's certainly up to the individual. I would think, I'll just say that if you're looking for a longterm relationship, I think honesty is one of the biggest components of successful longterm relationships. And I would think that disclosing Parkinson's would be something that would come up earlier in the relationship. Maybe not, obviously on a first time you're meeting someone, if you don't feel like you kind of know yet where things are headed. But I think it would be something that would want to be there earlier in the relationship development.

Larry Gifford: It probably also depends on your symptoms, your motor symptoms. Especially if you're getting dyskinesia every day, you probably need to explain why.

Dr. Camille Vau...: Why. Yeah. I think it's part of someone's medical health. It's not like we're always telling everyone. But I think in a relationship, even if you had a condition, maybe like high blood pressure where medications for that condition can also impact sexual function. That might be something that in a relationship you would want to disclose at some point if you're going to engage intimately so that someone knows what you're also living with. So I think it's not something that someone should feel like they have to share immediately, but I think it would want to be early on in their relationship.

Larry Gifford: Dr. Whitman, any advice that you'd like to add?

Dr. Daniela Wit...: Yes. What I would like to add is, I agree with everything that was said. What I would like to add is ... you know how when we begin to date and new people are kind of a little bit anxious to get started to develop a relationship and so on. I think that anybody who's got any kind of a chronic condition has to really look at who they are dating and assess fairly early on whether you're dating somebody who is a thoughtful person, a person who is compassionate, a person who is interested in learning about you much more than just the attraction.

Dr. Daniela Wit...: Because I think when you decide to disclose, you know you have testing, you're testing the person and you're testing whether they can hear the information, be interested in more, and you want to keep on assessing at any time that you disclose anything. Like for example, for us to disclose that you have Parkinson's before you ever talk about the sexual issues as a way of just testing where is this relationship going to be able to go? So I just would say, definitely it's important to disclose and be part of the conversation and part of the relationship in its fullness, but also just keep on assessing the capacity of the person that you're engaging with.

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Larry Gifford: We're going to move on to medications that can impact sex life, and then we'll get into some treatments. I'm going to start with a question for ... we'll start with Dr. Vaughn. Can cannabis impact your sexual libido positively or negative?

Dr. Camille Vau...: I would say, generally we think of cannabis as being more of a depressant for most activities that involve particularly in neurologic function. And so it does not generally enhance sexual function from kind of that perspective. I'm not generally recommending cannabis use. I know there's a lot of interest in kind of CBD oil and these other things, but we don't generally recommend a cannabis use in general for people living with Parkinson's, and then not for sexual function.

Larry Gifford: Great. Dr Whitman, do you see sexual changes more commonly in the early onset PD or the older people with PD?

Dr. Daniela Wit...: I think that there's more of an awareness of changes in the younger people because the change more dramatically impacts what they are used to doing. And younger people have probably more frequent sexual activity. So there is definitely an awareness that things are changing. There are a lot of emotions about what is changing in a sense that people as they are older and may have somewhat lower sex drive and less sexual activity, that is sort of less impactful. That's at least been my experience.

Larry Gifford: Well every time I go to the neurologist they asked me if I've been shopping excessively on the internet. They ask me if I have been hypersexual, they ask me

if I've been gambling. And oftentimes, it's because it can be related to some of the medications you take and-

Dr. Daniela Wit...: Right. It's the medicine.

Larry Gifford: ... they can cause those behaviors. Yep. Dopamine agonists are among those that have caused hypersexuality. Can you talk a bit about how that is, and then what you can do if you find yourself in that situation, Dr. Whitman?

Dr. Daniela Wit...: Yes. The research says that there is a possibility of having a hypersexual behavior as a result of being on the dopamine agonists, maybe gambling, other kinds of things that look to other people as kind of an addictive behaviors. They can cause disruption in relationships and serious concerns. It's been my discussion with urologists that they will change the dose of the medication to improve that. There can also be some behavioral interventions. But my experience has been more that it has been a matter of changing the dosage of the medication to kind of relieve that kind of activity. I think sometimes it comes on slowly, and it's very distressing and is very important to discuss it, to be able to address it. [inaudible 00:34:09]

Larry Gifford: Well, I'll tell you what, Dr. Whitman. I've talked to several people who have experienced this and they actually say it's fairly euphoric. They feel invincible and they don't realize that it's happening. Like they don't feel the pains of Parkinson's anymore and they feel like they are on top of the world when they're in this state. So it's almost something that needs to be monitored by the care partner.

Dr. Daniela Wit...: It's the partners who see it. Yes, absolutely. It's the partners who have to address it, and they have to address it with the physician because the person who's experiencing that euphoria is not necessarily going to reflect on it themselves.

Larry Gifford: And let's talk a little bit about the care partner. The care partner themselves can also be exhausted and depressed and have a lack of sex drive. Dr. Vaughn, what advice do you have for these care partners that are trying to balance being a wife or a girlfriend or a husband or a spouse and also a care partner? How do you balance that? How do you get over the exhaustion? How do you begin to look at who you're taking care of as sexy again? It's hard.

Dr. Camille Vau...: Right. And I don't want to minimize it to say it's something that could be simply answered. But, that relationship is built on many things beyond what has now occurring with Parkinson's. So, to the extent that if we're talking about kind of scheduling sexual activity, intimacy times, taking yourself out of the typical routines or if possible, even the environment that you're in on a daily basis, if it's feasible to have a getaway weekend, a staycation somewhere at maybe a hotel in town even. Not necessary, but that's just a way of kind of getting yourself out of your usual routine or environment. Maybe using favorite music

that you share together in your relationship. Looking at remembering memories of romantic times.

Dr. Camille Vau...: You talked about candles and whatever those things are that you have shared as a couple over the years that bring out the kind of romance, And really then think about the timing. Maybe the best time for both of you is at 10:00 AM, or 1:00 PM or something that's maybe a really nontraditional time for those types of activities earlier in your life together. Try to create that environment in a very intentional way and give yourself, give both of you more time to get in the mood, doing some of those things that aren't maybe the intercourse activities to try to bring on the kind of arousal that was talked about, because it might take a little more effort than it has in previous years of life.

Larry Gifford: And if the person with Parkinson's is going through a depression or apathy, they may be on some medication that could also lower their sex drive.

Dr. Camille Vau...: It is possible. One of the things that could be a way of entering into conversations with a physician or a nurse practitioner or app that's caring for you could be anytime a new medication being prescribed or maybe prescriptions even being renewed, if sexual dysfunction is one of the things that's been troubling, is to maybe ask at that time even, how will this medication change. Or new medication, will it have any impact on my sex life or sexual function, as a way of kind of opening the door to that conversation, too. I think with any medication there are obvious benefits and potential risks, or we hope there are obvious benefits, and there's usually potential risks. Even with depression medications, many of them may have some effect on libido, but certainly, not treating depression is not a good idea in the life of anyone, especially in those folks living with Parkinson's disease. So I think we have to kind of balance that obviously.

Larry Gifford: Go ahead, Dr. Whitman.

Dr. Daniela Wit...: I just wanted to do a mention that there are some medications that have greater and lesser sexual side effects. And so, speaking to a knowledgeable provider that can be sorted out, and whether the medications that do not have sexual side effects can be useful for treating the depression in the person with Parkinson's. That's one thing that can be done. And one of the things that antidepressants do is they have an effect on orgasm. They make it harder to come to orgasm, and it's very important for people to know that. And there have been times where between the provider and the patient, they have discussions about taking a vacation from an antidepressant for a day to be able to experience sexual pleasure more intensely. This is not something anybody should be doing on their own. It's only really in discussion with their physician. But this is something that definitely can be managed. And again, it's very important to balance, as was said before, the importance of managing depression versus optimal sexual function. Because anybody who's not going to be taking antidepressant medication is probably going to be depressed. That in itself interferes with sexual function. So it's important to ...

PART 2 OF 3 ENDS [00:40:04]

- Dr. Daniela Wit...: ... in itself interferes with sexual function, so it's important to treat the depression.
- Larry Gifford: Dr. [Vaughan 00:00:40:07], are there any interactions between the PD medications and erectile dysfunction medications like Cialis or Viagra?
- Dr. Camille Vau...: Yeah, that's a good question. I mentioned a little earlier that particularly levodopa, but the dopamine agonists as well may lower blood pressure. And one of the more common side effects of the medications for erectile dysfunction like sildenafil or Viagra, or vardenafil, or Cialis, or any of them really is that they can also lower blood pressure.
- Dr. Camille Vau...: So I think we have to be just thoughtful about looking at how blood pressure control is going for the individual, and be, again, looking at overall medications that are being used. For instance, if someone's also on the drug you mentioned earlier, tamsulosin, which also can lower blood pressure, we often are telling our men who are taking that to maybe not take the tamsulosin on the day that they're going to use a medication for erectile dysfunction like sildenafil, for instance.
- Dr. Camille Vau...: That's not something that we really can do as easily with the Parkinson's medications usually. And so, it might be looking at dose adjustments, at least, if low blood pressure is part of some of the conditions that someone's living with to make sure it's safe to use the medications for erectile dysfunction if they're needed.
- Dr. Camille Vau...: Or there are some other potential strategies to help with erectile dysfunction that might not involve those medicines if low blood pressure. But I'd say that's the main concern. It's not so much interacting with how the medications like levodopa work for Parkinson's, it's looking at that blood pressure issue that can sometimes come up.
- Larry Gifford: Can they lose their efficacy over time? If you use Viagra or Cialis over the course of time, does it lose its power?
- Dr. Camille Vau...: I don't think the medication loses its potency necessarily. But I've certainly had patients who've said, "That worked for me for a while, and then it didn't seem to work as well." And again, I think it's reasonable to look at a multifactorial assessment and see if there's other things that have changed in that intervening time that we could modify to try to help.
- Dr. Camille Vau...: It may be that the disease has progressed, and the impact on the nervous system that's responsible for erectile function or orgasm is also being impacted more. I'd say it's somewhat common in my practice, at least, to have people

come back maybe a few years later and say, "Okay, now what? What's the next step?", because they've had some... where it hasn't worked as well.

Dr. Camille Vau...: I also remind people, though, that even the medications for erectile dysfunction, like the injection form which most men don't want to do, which I don't blame them at all. It may be the only one that produces an erection. But even the medications, the pill-based versions, they create the environment to have an erection. They don't cause an erection.

Dr. Camille Vau...: So you still have to have stimulation, and arousal, and those other important pieces to the activity to have an erection occur. And there are windows of time that the drugs work. So I tend to find I have better success with some of my patients with sildenafil, which is Viagra, but it only works for about four hours. So you have to, again, be thinking about your window of time for activity. You've got about four hours, so that scheduling activity really comes into play.

Dr. Daniela Wit...: Sometimes it's useful to try Cialis, which has a longer term effect. But the other thing that some men have used quite successfully have been vacuum devices, which are nonmedical treatments for erectile dysfunction, which can be quite helpful in creating an erection. Pumping blood from the body into the penis, using a ring to trap the blood. And then 45 minutes to be engaged in sexual activity. So that's another option.

Larry Gifford: Go ahead.

Dr. Camille Vau...: I just want to say, I work for the Veterans Health Administration as well, and they will actually provide vacuum erection devices for people that receive their healthcare there.

Larry Gifford: That's good to know. Should everybody that's having these types of issues seek out some sex therapy? As you go along, we have physical therapy, we have other types of therapy. We've listed several here online, but is that something that you should bring into your care team?

Dr. Daniela Wit...: Well, personally I think that it's very useful. If sex is important to you, then it's important to have somebody who will be your educator, your advocate, and your just information provider. And sex therapists who are familiar with Parkinson's can be very helpful as collaborators with your physicians.

Dr. Daniela Wit...: It doesn't mean that you're in therapy every week. It just means that you may need to go in to evaluate where you are, what are some of the methods that are going to improve your sexual pleasure and also your sexual relationship in this new setting? And that can be a once in a while visit. There are people who have relationship issues that really would benefit from sex therapy.

Dr. Daniela Wit...: But I think just having somebody who understands that sex is important, who's familiar with sexuality and the impact that chronic conditions can have on it, I

think can be very, very useful. They're not that available. There is a website, AASECT, I can provide it later, dot org, which lets you know the location of every certified sex therapist in every state in the United States.

Larry Gifford: Oh, that's great. That's great. Yeah, we'll pass that along. We'll put that in the resources list.

Larry Gifford: And then, we've talked about some of the pills you can take, and the topical therapies. We've mentioned injections and lubricants, vacuum devices and vibrators. What's the surgery that you would have?

Dr. Camille Vau...: There is a penile implant that can be done by a urologist to provide a mechanical way to create an erection. And so, that's certainly an option, and is something that a urologist would typically be the person to consult with, the type of doctor to consult with about that option.

Dr. Daniela Wit...: There are a couple of different types of those devices. Some of them require a fair bit of manual dexterity, so they may not be the best implants to use. And some are just simply bendable implants. And again, this is a pretty major intervention and surgery. So it would have to be very much in the context of understanding the importance of sexuality, the importance of intercourse, and the desire to have that capacity.

Larry Gifford: I want to loop back now to a topic we've already discussed a little bit, but I want to go into more detail. There's a lot of people, both men and women, who are chiming in on the webinar who are bringing up the inability to achieve orgasm. And if you have some advice for them on how they can solve that issue?

Dr. Daniela Wit...: The main thing to do is to try to be sexually active when very well-rested. Fatigue can really influence the ability to have an orgasm, so that would be the first thing to be aware of. The other would be if manual stimulation or intercourse doesn't do the job, then definitely vibrators can be useful using plenty of lubricant, and allowing oneself slowly and gradually move in that direction, trying to be relaxed, create an erotically stimulating situation. But I would say vibrators are excellent.

Dr. Daniela Wit...: For women, there is a clitoral pump that also exists. If you look on the internet, it's called EROS, and that brings blood into the clitoris. And that can help then with stimulation to bring to orgasm. The last thing I want to mention is that men can use vibrators, too, not just women, to stimulate their scrotum, to simulate their penis. To just be playful, take time, but definitely be rested.

Larry Gifford: You talk about this in such a casual way, Dr. Whitman, and for a lot of people this is very new ground. They can be fearful of it, they can be embarrassed by it. How do you discreetly go about obtaining a vibrator?

Dr. Daniela Wit...: You can go to an internet location called goodvibes.com that's a pretty bonafide place to look at their products, and then they will mail them to you.

Larry Gifford: And the mail carrier's not going to go, "Here's your vibrator." It's going to be in a discreet packaging, right?

Dr. Daniela Wit...: Yeah. There's not a picture of it on the packaging, no.

Larry Gifford: Well, if you've never ordered it before, it may be intimidating. The same thing with vacuum devices.

Dr. Daniela Wit...: I will say something about that, and that is if you travel with a vibrator, or with a vacuum pump, just put it in your luggage that you check through, so that they don't open your luggage and then you have to explain why you have those things when you go through TSA.

Larry Gifford: That is a great tip. That's terrific. And then, we have some other questions here that we're just going to run through as we have our final eight minutes of the webinar here. Somebody's asked about testosterone supplements. Are they helpful in this situation?

Dr. Camille Vau...: I'll just say that there have been several studies that have come out in the last few years that National Institutes of Health funded looking at testosterone in older men. Not necessarily in men with Parkinson's. So these are looking at men as they get older, specifically.

Dr. Camille Vau...: I will tell you, they had about 700 men enrolled in these studies. They had to screen 50,000 to find the 700 that qualified, based on a lot of different exclusion criteria for the study that tried to rule out... Men with any cardiovascular disease were excluded, or obstructive sleep apnea, or of course any history of genitourinary cancer or anything.

Dr. Camille Vau...: We see a fair number of men sometimes being placed on testosterone, and there are potentially some benefits for specific symptoms. Certainly if they have very low testosterone, it may help with sexual function, it may help with some fatigue. But largely it's a very small percentage of men, even in the general population, that are going to benefit from testosterone therapy.

Dr. Camille Vau...: The other is to really diagnose low testosterone, it needs to be measured at the same time, three days in a row at an early morning testing time when the blood sample's taken, because testosterone levels vary in an individual throughout the day. And so, if you're measuring it at different times, you may get incorrect information. So, that's all just to say that-

Dr. Daniela Wit...: [inaudible 00:12:06].

Dr. Camille Vau...: Yeah. So I'd be curious about your input, Dr. Whitman, but I just find very few men where it really probably is useful because of those things.

Dr. Daniela Wit...: No, I quite agree. I quite agree. And the critical point that you just made was, it's not really based on the sexual symptoms. It's based on low testosterone. So a man who's got erectile dysfunction or low libido, but has normal testosterone, that would not be a situation where anybody would supplement it.

Dr. Daniela Wit...: It would have to be associated also with low testosterone. And it really is a plus minus experience for men. I think that it always seems like such an attractive solution, but I think it's not quite as successful as we all wish it would be.

Dr. Camille Vau...: I agree.

Larry Gifford: Let's go through some rapid fire questions here, so we get as many in as possible. DBS. Does DBS surgery, as people are contemplating that, or have had that, does that have an impact on sexual changes?

Dr. Camille Vau...: Yeah, right. Deep brain stimulation. I'm not aware that it negatively impacts sexual function. And again, as it may very much help motor function in particular, and potentially lower the need for some of the other medications, the dopamine medications, probably, again, if it does have any kind of impact on sexual function, those types of benefits would outweigh that.

Larry Gifford: Great. Dr. Whitman, one for you. People who are trying to navigate sex and relationships with people with Parkinson's who have cognitive decline or dementia. What's the advice there?

Dr. Daniela Wit...: That really does come up in discussions. And I think that it causes a great deal of pain for the partner, because they may begin to feel that the person that is wanting sexual activity with them is no longer the person that they knew for all these years. Because now this is becoming more instinctual and less oriented towards them as a person where they have a history of sexual intimacy.

Dr. Daniela Wit...: So I think sometimes partners feel guilty and uncomfortable about limiting or discontinuing sexual activity. And I think that it's important for the partners to examine their own feelings about it, and proceed accordingly. I think that physical contact and sexual activity is always pleasurable and sweet. But I think that if there is no longer mutuality, I think it's legitimate for the partner to question how much they want to be involved.

Larry Gifford: Okay. Dr. Vaughan, how do you know the difference between hypersexuality and a strong libido?

Dr. Camille Vau...: Well, I would say that hypersexuality is when the behaviors are starting to disrupt other relationships. And so, if the care partner is starting to complain, or if the interest is leading to destructive behaviors that are impacting other

relationships because of sexual addiction, or staying up all night looking at websites with pornography, or that kind of thing, then that's when I would classify it as something that's more of a concern that we should try to intervene upon.

- Larry Gifford: Okay. And then also, real quick, ultrasound wave therapy for erectile dysfunction. What do you know about that?
- Dr. Camille Vau...: That is a new one for me and I will look it up. But maybe Dr. Whitman has experience.
- Dr. Daniela Wit...: I think that this is very much in the experimental phase. I would not recommend that anybody undergo this unless it's in a randomized controlled trial that somebody legitimate is undertaking. It's not a treatment option at this time.
- Larry Gifford: Oh, right. Well, I want to wrap this up real quickly with some tips. Again, we want everybody to be open and honest with their-
- Dr. Daniela Wit...: Larry?
- Larry Gifford: ... partners. Yes?
- Dr. Daniela Wit...: On the earlier questions, "Any advice for the LGBT community?"
- Larry Gifford: Oh, yes. That's important.
- Dr. Camille Vau...: Yeah. I just really wanted to speak to that because I think that in healthcare, LGBT community folks feel very marginalized and not responded to because nobody addresses specifically their needs. It's very important for people with Parkinson's who are gay, or lesbian, bisexual, or transgender to build community. And I think that support systems for people with Parkinson's, just like this foundation or other organizations, can help people connect, so that people can build community and support each other, and learn to understand their specific challenges.
- Larry Gifford: Great, thank you. Dr Whitman, Dr. Vaughan, thank you so much for your expertise.
- Dr. Daniela Wit...: Thank you for inviting. Thank you.
- Dr. Camille Vau...: Thank you.
- Larry Gifford: Thank you all for attending. I hope you have a great day, and thanks so much.
- Speaker 2: [music 00:57:20].

Outro: Thanks for listening. Community members like you are bringing us closer than ever to a world without Parkinson's disease. Learn how you can support the Michael J. Fox Foundation in its mission at michaeljfox.org.

Speaker 2: [music 00:17:41].

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PART 3 OF 3 ENDS [00:58:05]