Episode 63: Navigating Sexuality and Intimacy with PD

[music]

Dan Keller: Welcome to this episode of *Substantial Matters*: *Life and Science of Parkinson's*. I'm your host, Dan Keller. At the Parkinson's Foundation, we want all people with Parkinson's and their families to get the care and support they need. Better care starts with better research and leads to better lives. In this podcast series, we highlight the fruits of that research. The treatments and techniques that can help you live a better life now, as well as research that can bring a better tomorrow.

People with Parkinson's disease may experience changes in sexual function, which impact not only themselves but also their care partner. These problems may be complex, related to symptoms like pain, limitations in movement, fatigue, and sleep disturbances, as well as emotional changes like anxiety and depression. Adverse effects of medications may also lead to sexual dysfunction. All these changes can affect intimacy and sexual experiences, leading to dissatisfaction and discord in a couple's relationship at any stage of the disease.

Couples may hesitate to bring up these problems with their care team members, out of embarrassment, or because they do not consider them as central physical attributes of PD, but as with all symptoms of the disease, the goal is to treat them as well as possible in order to improve quality of life today. I spoke with certified sex therapist Gila Bronner of the Sheba Medical Center in Israel about some of the sexual and relationship problems that may arise as a result of PD and she offered advice about ways to overcome them. She first said it's important to think of the issue of sexuality in the larger context of relationships.

Gila Bronner: Because many people by mistake, or maybe according to our basic education, we usually refer to sexuality as only sex, meaning having intercourse or trying to reach some sexual satisfaction, but it's not. Sexuality is much more than this. Sexuality has a few aspects, which are non-erotic like the physical aspect of touching and hugging and giving one another a pleasuring touch. A touch which is so important to reduce our stress, to feel that we are important to someone. Sexuality has also the emotional part, where we care and we share love, and we show we really care of one another.

These aspects of sexuality create a type of intimacy, which gives us a feeling that we are good, that we are cared for, that we are important for someone. That's why it is very important. The erotic part of sexuality, like getting attractive, excited, aroused, stimulated, and even reaching orgasm is important, but this is a small part of sexuality. Why do I talk about it? Because many times when people have problems in their erotic part of sexuality, meaning they have problems in engaging in intercourse, they stop everything. They cancel any intimate reaction, and the damage is huge because we lose all these sources of getting good quality of life.

Dan: Why is it important to talk about sexuality and intimacy, and talk to them with whom?

Gila: It is important to talk about it because the frequency of sexual problems among people with Parkinson and among their spouses is very big. We are talking about at least half, if not more, of couples with Parkinson, where many times both of them will suffer from some sexual problems so we have to talk about it. The other reason that we have to talk about it is that many symptoms of Parkinson affect the ability to touch, to hug, to be close, to concentrate, to get excited, to get even sexually excited. We have to refer to them because some of them we can treat.

You ask to whom we should apply, this is not easy because, unfortunately, in many places, you will not have expert in sex therapy or in sexual medicine. What I suggest is try to talk to a professional with whom you feel comfortable. It can be your neurologist. It can be your GP. It can be another health professional, which you are working with like the physical therapist, the occupational therapist, the speech therapist, the social worker, the psychologist, share with them the problem. Maybe they will not solve it, but they can refer you to someone.

For example, in the United States, you have urologists who treat usually men with sexual dysfunctions. Some of the gynecologists can help you, but you also have an organization which is called AASECT, American Association of Sex Educators, Counselors, and Therapists. If you open the site of AASECT, you can find if you have sex counselor and sex therapists in your state. In other countries, you have to look for the association of sex therapists and look also at the general health services, and see if you have some kind of sexual health, or sexual medicine, or sex therapy services.

Dan: What kinds of problems and what categories of problems are there for people with Parkinson's disease?

Gila: Basically, we can divide them into two main groups. One is the decreased sexuality, meaning problems of, for example, low desire, low ability to function. The other one is increased sexuality. Let's refer to the first one. If we look at Parkinson's symptoms, I mean the motor and the non-motor symptoms, actually, each one of them can create a sexual problems. For example, if you have motor problems like rigidity or tremor, and you want to hug your partner or even you want to hug your grandchild or to caress a baby, you might have problems in your intimate relationship. Then your desire is decreased because you are so frustrated with what happens to you. This is one example.

Another example, many people with Parkinson have sleep problems. When you have sleep problems and sleep is important, so sometimes you separate beds, sometimes you separate your rooms, then you have to find a new solution. For example, even if you sleep in separate rooms, try to make a date once a week or once in two week, and sometimes you invite your spouse into your room for a chat, for a hug, for cuddling together, or maybe for trying to sexually and erotically stimulate one another. Then after a week or two or three, your partner will invite you. Just remember what you did when you were young people. This is the sleep problems.

Then we have sometimes urinary incontinence and urinary problems. You know when you have incontinence during intimate touch activity or sexual activity, it is uncomfortable and usually, it reduces your desire. We have to treat the incontinence and find solution, when can we have sex? The idea is that we can find what is affecting us, and trying to solve some of the symptom to reduce them.

Dan: It sounds like this would be making a change in behavior, and changes often don't come easily. Do people have to just keep working at it?

Gila: Yes, you are right. Actually, for most people, young people, adult people, middle-aged people for everybody, making a change in sex or in sexual activity is really difficult. You have to practice it. You have to plan it, so it looks as if it is not spontaneous and it is artificial. Many times, it takes time until you get used, until you enjoy it. Don't stop from trying, because we make change. Look, during life, we make changes in our eating habits, in our nutrition, sometimes in our walking habits. If you have Parkinson, you make many changes in your motor and non-motor life.

Make the change, but for making the change, you have to communicate with your spouse or to communicate with your health provider. What we have to do when we have to make a change is not start from negative disappointing point. Just start the change. Of course, it will be difficult. Even if you try now to do a new form of swimming or you will try to learn a new language, it will be very artificial and difficult at the beginning, but then you start to enjoy it. Don't stop from trying to make the proper changes that you need.

Dan: The other problem you identified is increased sexuality at the other end of the spectrum. What goes on there?

Gila: The increased sexuality means actually that there is an increased interest in sex. Here we have to differentiate two main phenomena. One is normal one, meaning that if you, as a person who is Parkinson, you receive dopaminergic levodopa treatment, then it restores some of your desire, your general desire, not only sexual desire, but it restores it. Also, if you get proper treatment for your walking, for your sleeping, you get information, you get education, then you feel better. Many times, we did not make this effort to help the spouse and the spouse is left with burden. Sometimes with new roles that the spouse didn't take on before with responsibilities and with a lot of anxiety.

What happens? A gap is created. I mean sexual discrepancy or sexual desire discrepancy is created between one partner and the other. Let's say, for example, take a man who has higher desire or good desire, not very high, but he has a desire, and the wife, his wife is so busy and so tired that she cannot find any moment for desire. This is one issue which we have to treat. What I suggest is talk between yourself, try to reduce the burden of the wife, and maybe even leave erotic sexual activity aside, temporarily, but invest more in hugging, touching.

Your wife is running all day long, offer her a foot massage, offer her a back massage, but don't offer sex immediately after that because then it's like a meal when they feed you with first portion and then they force you to eat everything else. Don't do it because then you spoil everything. If you concentrate on the intimate, non-erotic part, then you come close together, then you can talk about how to solve the sexual desire discrepancy that you have. If you have a specific problem, like erectile dysfunction, you can go to your family physician or urologist and maybe get a good treatment but do the first steps that they offered. This is the normal part of the increased sexuality which we can cope with.

The other one is actually part of the impulse control disorders. These are the unwanted and unwelcomed side effects of the dopaminergic treatment. We mean a person become compulsive with the desire to have sex. Usually, we see it in men. These men will be very busy, very active in looking for sex, trying to have sex, paying for sex. This is a problem that we have to solve. We have to solve because it's an inappropriate sexual behavior. Many times the partner, for example, if it is a man, the partner, or maybe a woman, she might be abused by the man with compulsive sexual behavior because he tries to have it all the time.

This created more burden on the wife, more stress. Usually, depression and anxiety are at risk. In addition, a person who deals with sex all the time is under a danger of various sexual health risks. For example, a risk of having AIDS, HIV, sexually transmitted diseases, the risk of abusing someone or being abused, harassing sexually someone or being sexually harassed. That's why we have to talk about it. This is a problem that you have to go immediately to your neurologist and try to adjust the medication in order to reduce this behavior.

Dan: For all of these problems that you've just talked about, it sounds like communication is the key. It depends with whom but you got to talk to someone and bring up the problem and try to solve it.

Gila: I'm very glad that you say it because I want to refer to younger couples in Parkinson. I mean at the first stage of Parkinson when it is early and the symptoms are not that bad. What I suggest to all these couples, in the beginning, start talking and communicating about your intimacy and sexuality because later when the burden is so heavy, when the stress is big, when you have so many symptoms that you have to cope with, then it is more difficult to communicate on intimacy and sexuality in spite of the fact that each one of you needs so much a hug or a kiss.

Now I would like just to offer one exercise or homework. If you have a possibility to hug someone like you have a partner, just once a day, take a minute, just one minute, stand in front or facing one another and put your hands behind the other in order to do a hug. Don't move your hands unless you have tremor but you don't move, you are not massaging. Just holding one another, listening to your breathing, listening to the breathing of your partner.

If it is difficult because you have postural instability, do the same when you lie in bed. Lie near one another, just hug one another, close your eyes and get the best medication that you can have to reduce pain, to reduce anxiety, and be a little more happier. Don't have any intercourse after that. The hug is a uni entity for itself and we don't combine it with anything unless you want to share, communicate, and talk after that.

[music]

Dan: Our website has many resources on this subject. Visiting parkinson.org/sexualhealth will provide you with more information on intimacy issues, sexual health, and how PD and its treatment affects sexual functioning.

Subpages cover male and female sexual health, pregnancy and Parkinson's treatment options, and the impact of sexual health problems. You can also visit the PD library at parkinson.org/library and type intimacy in the search bar. There you'll find several resources on sexual health, including fact sheets, an expert briefing by Gila, publications, and a podcast episode on autonomic problems.

By searching, how do I talk to my physician, you'll find a short video presentation by Gila in which she discusses tips for navigating the intimacy discussion with your physician. As always, our PD information specialists can answer questions and provide information in English or Spanish about this topic or anything else having to do with Parkinson's. You can reach them at 1-800-4PD-INFO. For questions about the topics discussed today or if you want to leave feedback on this podcast or any other subject, you can do it at parkinson.org/feedback.

If you enjoyed this podcast, be sure to subscribe and rate and review the series on Apple Podcasts or wherever you get your podcasts. At the Parkinson's Foundation, our mission is to help every person diagnosed with Parkinson's live the best possible life today. To that end, we'll be bringing you a new episode in this podcast series every other week. Till then, for more information and resources, visit Parkinson.org or call our toll-free Helpline at 1-800-4PD-INFO. That's 1-800-473-4636. Thank you for listening.

[music]

[00:19:13] [END OF AUDIO]