



Transcript

Welcome and Introductions

Stephanie Paul

[Slide 1] Welcome everyone and thank you so much for joining us today. **[Slide 2]** My name is Stephanie Paul, and I am the Vice President of Development & Marketing at the American Parkinson Disease Association or APDA for short.

I'm pleased to welcome you to this telephone and Web education program designed for people with Parkinson's disease, care partners, family members, and healthcare providers. APDA is pleased to bring this Web conference to you today.

APDA is the largest grassroots network dedicated to fighting Parkinson's disease and works tirelessly to assist the more than 1 million Americans with Parkinson's disease live the best life in the face of this chronic neurological disorder.

Founded in 1961, APDA has raised and invested more than \$170 million to provide outstanding patient services and educational programs, elevate public awareness about the disease, and to support research designed to unlock the mysteries of Parkinson's that will ultimately put an end to this disease.

To join us in this fight against Parkinson's and to learn more about the support APDA provides across the country through our network of chapters and information and referral centers, as well as our National Research Grant Program and Centers for Advanced Research, please visit us at apdaparkinson.org.

APDA is so proud to support those living with Parkinson's by helping them live life to the fullest every day. We do this each year by providing more than 1,700+ support groups that serve more than 75,000 people with Parkinson's and their family members through running 770+ exercise groups attended by more than 21,000 participants. These exercise programs help improve symptoms of Parkinson's and lessen the impact of the disease.

We also offer educational symposia across the country on living well with the disease. These programs have been attended annually by more than 5,500 people impacted by the disease. It's programs like these that distinguish APDA as the national organization working one-on-one with the Parkinson's community to make each day better.

And now to our program. **[Slide 3]** Our presenter today is Dr. Sheila Silver, who is a board-certified clinical sexologist. She maintains a private practice in Portland, Oregon, and is a member of the American College of Sexologists and the American Association of Sex Educators, Counselors, and Therapists, and the Society for the Scientific Study of Sexuality.

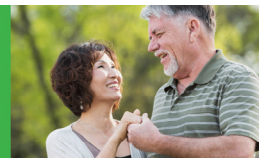


Today we are delighted to have Dr. Silver share an overview with us about how to embrace communication and intimacy for people with Parkinson's disease and their partners.

After the presentation, we will open up the program for questions from both the telephone and Web participants. We encourage everyone on the line to complete the evaluation after the program because your feedback is instrumental in helping us plan for future educational offerings, including teleconferences like this and other programs.

You may view the materials for this program and today's slides by clicking on the Resources tab on your screen.

It is now my pleasure to introduce Dr. Sheila Silver.



Presentation

Sheila Silver, MA, DHS, ACS

Hi, Stephanie. Thank you so much. I'm so happy to be invited to be part of this series.

[Slide 4] I want to begin by talking about communication and its importance in both emotional and physical intimacy. I don't think you can have true intimacy without the ability to communicate with your partner. And for emotional intimacy, there needs to be a sharing of hearts and of conversation. And for physical intimacy, it's the same. We need to be able to have that conversation.

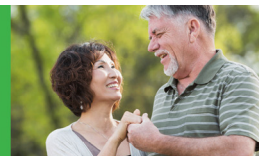
Certainly, if there's a health challenge like Parkinson's disease, it is even more important for couples to talk about their intimacy. But what often happens as a result of Parkinson's, or simply just normal aging, is our bodies and our sexuality begin to change and become less reliable in their responses. And when this happens, couples often shy away from sexuality out of shame or fear or frustration or embarrassment or simply really not knowing what to do about the situation.

So, couples often do one of two things. They don't talk about the problems, or they simply stop being sexual all together. Sometimes couples try to have a conversation, but it doesn't go well so the topic is avoided in the future. And so today I want to begin by just offering some suggestions of ways to sort of restart that conversation and how to be more successful at it.

So, the first slide here shows that the way to begin really is to have a shared goal, to realize that you're coming at the conversation with the desire to be closer to each other. You're not trying to be critical or trying to complain about things that if you're coming from the position of really just wanting to be closer to the other person, then there's a way in which the other person isn't going to be as defensive; and they can share that goal with you.

And so, my encouragement is to be brave and vulnerable in having this conversation. What I mean by being brave is to actually have the conversation. Many of us didn't grow up in families where we talked about sexuality, and early on in our relationships there hasn't been a need often because our bodies are working fine and things go along smoothly. But at some point, as we grow and change and our lives get busier and we have health challenges, we actually need to talk about our intimacy and that can be challenging, and we don't have that skill. And so, coming at it with a realization that it's a hard conversation but it's an important one to have.

And starting with some vulnerability is a good way to begin, to talk about what you're experiencing yourself, rather than what the other person may be experiencing or what you're noticing about them or their body, talking about what you're noticing as you're aging or how your body's changing with your health issues, whether you're the patient with Parkinson's or you're the care partner. You can come at that conversation from a place of vulnerability; and that, again, helps the other person just listen and hear what you have to say and then look within themselves about what they are feeling vulnerable about.



And then, hopefully, you can bring some ideas to that conversation, things that you'd like to try or do differently. Certainly, at the end of this webinar, you'll have some ideas. But even if you don't have ideas to bring to the conversation, it's still worth having; and it's a good idea sometimes to get someone to help you have that conversation. And a little later in the program I'm going to talk a little more about that.

But, ultimately, what you're trying to do is just create a win-win in this conversation. You're trying to see if there's a way each person can get a little more of what they want or a little less of what they don't want.

[Slide 5] The next slide is just a few more hints; and the first thing it says there is talk before, during, and after sex. And sometimes when I make this suggestion to couples, they're a little taken aback because they're not used to talking before, during, or after. But I compare it to having a meal; and if people go out to dinner, they often will have a conversation ahead of time about where they want to go and how far they want to drive and whether they actually really want to bring take-in or something like that. And so, there is a conversation and a bit of planning that happens with that. And then when people are actually at the meal, they're often trying to look at how can they make that experience even better? Would a glass of wine be nice? Would they like a little extra salad dressing with their salad? And so, there's conversation during, looking at and commenting about what's lovely and what they're enjoying and sometimes what they're not enjoying. And so, after sex sometimes, or after a meal, you can also reminisce on the drive home or the next day about what was something really good or wonderful about that experience.

And so, I think sex is very similar, and there's actually no reason why couples can't sort of follow that same plan. Having a conversation, even however briefly—it doesn't have to be a long talk—but just a few sentences about what do we feel like. Here we've maybe created some time to be close and physical in some way. What do we feel like? Where do we want to start? What sounds good to us? Having that conversation beforehand can be really helpful so that people are on the same page and have the same expectations.

And then sometimes during a sexual encounter of some sort, asking for what you want or want a little differently, and sometimes that can happen through words or just moving someone's hand. But holding that question of what do you want, and what would make it even better? Perhaps somebody moving their hand a little slower or a little faster or a little less pressure, a little more pressure. And so sometimes guiding somebody to what you do want is very helpful, rather than just saying, "Oh, I don't like that or I don't want that." That often doesn't give the other partner something to do. So, giving them something to do differently that you think you might like or you know you would like can be very helpful.

And then I always encourage my couples after they've been sexual in some way to sort of reminisce about it or talk about it. What worked well? What was your favorite part? What might you do differently next time? I think that can be very helpful in creating future good experiences and, also, as a way to create intimacy in letting your partner know what's special and what was most meaningful about what you guys did.



Ultimately, sharing the problems as allies is a really important perspective, that it's not one person's problem, but that it's actually your shared problem. If there's bumps with somebody, their body not doing what they want it to do or your body not responding the way you had hoped. If you can think of yourself as a team, and this is something that we're facing, then you can be often much more successful in solving that.

So, if you want to find someone to help you with these conversations, this next slide shows you some alternatives. **[Slide 6]** One of the first places to go that's not even listed here is to consult with your doctor. If you're noticing that you have sexual side effects from medications or your Parkinson's is actually creating a real change in your sexuality that you've never experienced before, definitely the first person to talk to is your doctor and ask them about the medications you're on. Ask them if there's something that they could do differently, and usually both the care partner or the spouse needs to be part of that conversation as well as the patient.

But if you want a therapist of some sort, you can certainly go to the American Association of Sex Educators, Counselors, and Therapists, and I've listed their website there; or you can go to the American College of Sexologists, and there are people on both of those websites who are listed by state and by city, and there may be somebody right in your area that could help you with that conversation, and sometimes it's just one session or two sessions with a person that can really help facilitate that conversation and make a big difference in terms of your physical intimacy.

You could also contact a social worker who's part of your health team or part of your health center. Social workers who work with people with Parkinson's are very comfortable talking about sexuality. They know that that's a challenge that anybody with Parkinson's is usually facing, and so they're a good resource for you. Or you could just have a Skype or Facetime call with someone who's trained in another city and have them, maybe through the Internet, try to help you. And that can be helpful if there's no one in your area.

[Slide 7] So now, I want to talk just about the physical/sexual challenges that patients experience. Some of these you may be already experiencing, but I'm wanting you to know that they're very normal things that you can anticipate. Slowness of movement, obviously, the tremor and the rigidity that comes with Parkinson's, obviously, often will interfere with lovemaking. Having a reduced sexual interest or desire, this can be due to just the fatigue that comes with Parkinson's or it can be a complication of the medications that you're on.

Men often struggle with getting or keeping erections; this is very common or getting to orgasm. That's something that is a result of having Parkinson's, given that it's affecting your central nervous system. And so, I'll be talking later about ways to work with that.

Women experience dryness and pain sometimes, and they also struggle with orgasm. This can be related to the Parkinson's specifically or to the medications that they're on. And then there's always some facial animation that's diminished in some way, and that's related to sexuality in that we often look to our partners for nonverbal cues of whether they're interested or not interested. And when there's a diminishment in the facial animation, then there's a way in which sometimes it's harder for a Parkinson patient to sort of be able to be read by their partner, and so that can affect the challenges.



[Slide 8] The next one is emotional challenges for patients, and these are things that also definitely affect sexuality. It's not just the physical aspects that are complications. So, having some sort of negative body image about how your body is looking or how it's behaving in a certain moment often can make people more shy or a little more unwilling to even engage sexually.

Depression, of course, is a symptom of Parkinson's and makes people a little more uninterested in being sexual or the grief that comes along with their changing bodies and their future and worry about some of that. So, all of that leads, sometimes, to just a reduced level of self-esteem; and so, there's a way in which they just don't want to participate in something that feels like they need more energy behind.

Communication difficulties can happen just from some thinking aspects. If there's some cognitive changes that's happening for a Parkinson's patient, then sometimes just communicating about what they want or what's happening can be hard. And then there are attention issues that come with Parkinson's that sometimes affect the whole ability to stay focused. Often for Parkinson's patients, they can only focus on one thing at a time. And so, when there's distractions when you're trying to be sexual, it can really upset what would normally be a more smooth-flowing experience.

[Slide 9] And then I want to speak a little bit about the challenges that partners face because I think it's important that patients realize what their partners or spouses are experiencing sometimes that may be different from them. So, one example is the changing roles, from going from just your partner, your lover in some way, to care partner. There's a way in which partners are managing often medications or doctors' appointments or various things that need to be taken care of as a result of the Parkinson's. And so, what we know is that when we take care of someone like when we have small children or we're involved in taking care of a family member or a friend, it really diminishes our sexual interest in a lot of ways. We're in sort of more of our mom role or our father role, rather than in our lover role. And so, there's a way in which, for partners, they have to be more intentional sometimes of really switching out of that role, of leaving that behind when they're wanting to be sexual, and just trying to come at it as just a person without the roles.

Patients, too, need to be aware of that, that they're not holding this role of being a patient; but they're also really aware of the fact that they are just a person as well, so that's important and that can be a challenge. Tiredness from taking on more responsibilities is certainly something that many partners face. Their own fear, their own worry, their own anxiety—both about their partner and about themselves and their own future and how are they going to manage this? So that can affect partners and their interests in being sexual.

Sometimes there's a loss of sexual interest due to Parkinson's symptoms. We've talked about not being able to read nonverbal cues, and sometimes there's just a loss of emotional connection if there's less talking or there's more maybe friction around this new health challenge or maybe old health challenge for people that have been diagnosed for a long time. So, all of those things are challenges that partners experience among other things as well.

[Slide 10] So one of the most important things to really remember and think about is how we even think about sex. There's a way in which often in our culture we think about, when somebody says sex,



we think we know exactly what they mean; and usually they're talking about penetrative sex in some way. And what I would like to invite you to think about is sex as more of a buffet. It's a buffet of different sexual things that you can do with someone or sensual things that you can do with someone, all of which are options. But on any particular day or moment, that may not be what you want to do. That may not be what your body is capable of doing. And so, if you can pick and choose from the menu, if you can pick and choose from different options, of ways of interacting that are sensual or sexual, it broadens the options of what you can do and how you can be physically intimate.

And so often what couples need is a little extra help in sort of broadening their menu. There may be a way in which they've only sort of done a few things, and it's been a pretty set pattern. And so, what is being asked as we age and having health issues is that we really need to expand our sexual pattern. We need to maybe make some adjustments to it because our bodies aren't responding the same way. They're not capable of the same things. Sometimes things hurt in ways that they never used to, and so enjoying sensual touch or just nondemand pleasuring in some way—and what I mean by that is that there's no agenda, that there's nothing that has to happen. Nobody's body has to do something in particular. There's not necessarily an erection needed. Somebody doesn't have to have an orgasm. There's just a way in which people can just touch each other for the point of connection and pleasure, rather than because they're expecting something of themselves or their partner. And so being open to orgasm in nonpenetrative ways or it not happening at all and somebody still really enjoying that physical connection is helpful, and it helps you broaden what is possible and ways of actually being close and connected.

[Slide 11] So thinking of physical intimacy as a buffet means that you make everything that you engage in sensual and sexual but all about pleasure. That that's the goal. The goal isn't to try to accomplish a particular activity. Intercourse may or may not happen. Orgasm, as I said, may or may not happen. We sometimes want those things to happen, and sometimes our bodies are just not there. That's not what they are capable or wanting to do for a variety of reasons.

And so, I think what's most important is that you have to look beyond what you think should be happening, what's supposed to be happening, what you usually do maybe as a couple, and listen but more towards what you want. What do you really want to have happen in that moment rather than what the person's expecting of you? Now maybe what you really want to have happen is just not possible, and so what you need to look at is what is possible? What would be fun? What would be enjoyable? What would feel good to my body? Or what are you a yes to? For people who struggle with desire, I think looking instead of not at what you don't want, but looking at what you do want is a more helpful question. And so maybe it's just touching the other person's body with your whole body, and that's the destination. So, looking at more options in that way.

[Slide 12] So I do want to say something about desire because I often get this question that sexual interest and desire really changes with Parkinson's, and so I think something that's important that everyone understands is that often desire is responsive, rather than spontaneous. And what I mean by that is for some people they just walk around interested in being sexual, and typically this is men because they have more testosterone in their bodies. But often for women, and for many men, their desire really is in response to something. So, it's in response to touch, it's in response to something



that they're thinking about, or it's in response to something that they're read or looked at; and so, the desire kicks in once something's happened that they feel is sort of sexually arousing in some way. Sometimes it can just be a conversation that they're having with a partner or a romance novel that they read or something. But I think it's good to not have the expectation that desire is something that I should just be having, that spontaneously it should exist before I even start. I'm inviting you to think about desire as something that kicks in after you start, and so what you really need is just a willingness to start. And so, what you can look at is what helps you form that willingness, and we're going to talk a little more about that in a moment.

But you're looking at what you do want to do, rather than what you don't want to do, and you need to be able to take responsibility for having what I call your own pilot light lit a little bit. So is there a way in which when you come to be sexual with your partner, you're expecting them to do all the work, that you're hoping that just by being with them you're going to get turned on. And I think that's a lot of pressure to put on another person, and it actually helps us if we take responsibility for kind of just getting what I say pilot light started and just noticing what could you do maybe beforehand to sort of get that pilot light started. Is there something that you could do that would help you be ready and willing to actually start some sexuality or some sensuality?

[Slide 13] So I call this bridging time, and sometimes women need this more than men; but often I've heard men find that even just working out helps them feel more in their bodies and more fit and more interested in being sexual and that's sometimes really helpful.

But it's, essentially, a buffer of time before you're sexual where you might take 10 or 15 minutes or half an hour or even an hour prior to maybe a naked date or a sexy date time with your partner where you're doing some things on your own. Maybe you're having a bath. Maybe you're reading something. Maybe you're just meditating or journaling. It's a way for you to drop into your body, reconnect with your willingness to connect with your partner in some way, in a physical way, and just trying to see what would help you get in that mood. And part of it is just letting go of the things of the day or maybe what you were doing that morning and trying to let that go, the doingness, so that you can just be with your partner and be with their body and let them be with your body. And so, I find for a lot of my couples that that's incredibly helpful is to just know that they need that bridging time and to kind of build it in.

[Slide 14] Okay, so the next slide is talking about just sort of soothing our fears because so many times couples with Parkinson's often, and just people who are aging, notice that they are afraid to be sexual because their bodies are changing, because they can't show up in the way they used to. And so, I think the most important thing is to just let go of the expectations, let go of what I should be doing or what they should be doing, and realize that sex changes as any relationship progresses. That that's really normal, and so you need to just let go of those shoulds and thoughts and just come back to your body. What would feel good? What kind of touch would feel nice and comforting and soothing and pleasurable and enjoyable and not having big expectations?

What I like to tell people is sexuality and intimacy is more than sexual functioning. Sometimes it's really not even about sexual functioning because that can really change and be affected by both



Parkinson's and the medications that you need to take when you have Parkinson's. And so instead you need to have the conversations about what you would like, what sounds good, offering touch to your partner in a way that they can give you some coaching about what feels good, and then just surrendering to the touch that they want to offer, knowing that you allowing them to touch your body in some way just feels like such a gift to them and that it's a way that you're close and connected in ways that are really intangible but help couples feel emotionally close as well as physically close.

[Slide 15] So making physical intimacy a priority, I really feel, is very, very important. So many times, couples want that to be a more spontaneous thing. That's how it is in the movies. It just sort of happens. But that's not my experience of certainly long-term couples or many, many couples is that they actually do need to schedule some time together.

I think what we put on the calendar is what's most important to us, and we end up not finding time to be physically close, especially when there's medications that you're trying to time and fatigue issues that you're trying to manage. It's all the more important for Parkinson's patients to actually schedule a fun date. You don't have to show up for it in an aroused place necessarily. You just have to start with a willingness, as I said earlier. I'm not talking about necessarily going out somewhere but just creating some time that you've blocked in your lives where you're just going to be close and connected in some way. And it may be having a bath together. It may be laying naked. It may be doing sensual or sexual things to each other. It may be touching each other's bodies, not as a functional massage but just in a sensual way. But prioritizing that and noticing what gets in the way of you not doing that I think is important.

People sometimes hesitate from that because they think it'll take the fun away from it, but I often say to them, "Well just because you plan a party or a vacation doesn't mean it's any less fun." In fact, the opposite is often true. You're anticipating it, you're looking forward to it, you're getting ready for it. So, I think it's a good thing for couples to do.

[Slide 16] And then connecting with your hearts is really about building the sort of building blocks for that physical intimacy we've been talking about. Creating that time where you feel physically close and emotionally close is very important, and some of it is a required, you're really needing to step away from TV and phones and the Internet. Some of it is just finding time to be together. Sometimes it's actually just looking into your partner's eyes. Many times, we don't actually do that. We're busy. We're with our partner maybe or not with our partner during the day, running chores or doing whatever we're doing; and I think finding that time to just breath for a moment and look into each other's eyes and say, "I love you," is a really important building block and foundation for a relationship.

Being compassionate with yourself, realizing that it's okay that your body is changing and it's not the way it used to be. Being present and kind with each other and showing up for each other and being close. Having shared activities that you do and having your own activities that kind of recharge you. And the last thing I have on this particular slide is emptying your frustration and anger tank periodically is very important, both for patients and partners. There's a way in which it's normal to feel frustrated and angry about what's happening, and I think unless you find ways to just let it go, either in



a physical way or in a way that's just writing in your journal or driving in your car and yelling or whatever you need to do, talking to a therapist can be sometimes really helpful. But I think if you empty that tank periodically, then you're able to come at a more emotional connection with your partner in a better way.

[Slide 17] So we talked earlier about talking to your doctor, and I really can't emphasize this enough that the doctor sometimes won't bring up the topic of sexuality with you, but you can certainly bring it up with them. And there are some things that they can do in terms of medications to sometimes help with sexuality issues, and so that really needs to be your first stop.

[Slide 18] And the kinds of questions you can ask them are, "can I talk to you about the changes in our sexual life or my sexual experience or what I'm noticing in my partner, he seems to be different." "Is this something you would expect? Could this be related to medications or just specifically asking what are the sexual side effects of the medications I'm on." These are all really good questions to ask of your doctor, and they're more than happy to answer them. And they also have referrals to give you if they feel like you could benefit from talking to other people about this as well.

[Slide 19] So just in summary, I just want to go back over the fact that communicating with your partner is so very important. I feel like I've just skimmed the surface on that topic, but it's something that builds both emotional and physical intimacy. Focusing your sexual interactions on connection and pleasure, rather than a particular outcome, is very important. Expanding your definition of sex, thinking of it in a much broader way, as a buffet of different things we can choose from, and each sexual experience is maybe a few things from the buffet and make being physically close a priority. Putting it on the calendar, making time for it. Even if it's 10 or 15 minutes of a cuddle, it doesn't need to be an hour. It doesn't need to be two hours. But finding that time on a regular basis with your partner is so important and then, again, talking to your doctor.

So, I will now turn it back over to Stephanie for questions.



Question & Answer

Stephanie Paul

Thank you, Dr. Silver. This is very informative and important information that you shared with our audience today. [Slide 20] It's now time for the question and answer session. Before the Operator gives instructions to queue yourselves for questions, I would like to remind all of you that we have hundreds of people on the phone and on the Web today. For everyone to benefit, please keep your questions general in nature and our faculty will provide an answer general in nature.

Dr. Silver will be answering questions that are focused on communication and intimacy. She will not be answering questions about medication and treatment.

Stephanie Paul

We will take our first question from the Web audience. We have Margaret from Ohio who has written in and has asked, "Can you speak a little bit about dating when you have Parkinson's disease? How do I talk about it with potential partners?"

Sheila Silver, MA, DHS, ACS

Great, Margaret. Great question. So, one of the most important things when you're single and you're trying to date is that you're upfront with your potential partners. Sometimes people will put themselves online but not mention that they have Parkinson's, and then they are very disappointed when they show up with a potential partner, and the partner's like, "Wow, this is unexpected."

So, I think it's important to be very upfront about that from the beginning. Yes, it makes it more difficult to get partners online; but I think it's easier to get partners in other kinds of ways when it's just known right from the get-go. And I think it's important to concentrate on being in the now. Often when I work with Parkinson's patients and they're worried about dating, they're thinking about their long-term future. And what I say to them is look at right now. Today, what are your needs? How interested are you in being a dating companion? How interested are you in being in a relationship for however long it may last? Somebody doesn't have to necessarily commit to long term for you to be dating and having some fun with a person. And so, I think it's just really important that you just live in what are you looking for right now.

And then I think it's also important to give potential partners a few clues or tools that they may need to know about you. You know, this is not a great time of day or sometimes I get distracted when people talk to me. And so, a good thing to do with that, if that were to happen, is for us to plan our dates at this time; or for you to, if you notice I get distracted when we're talking, to just bring me back and just say, "I notice you got distracted. Here, I was telling you about something."

I think if you do it in a kind way and you give them tools to work with, then they're happy to be in your company because you are more than your Parkinson's; and I think that's the most important thing to



remember is that you are more than your disease, and you have a lot more to bring to a relationship than just that.

Stephanie Paul

That's great. Thank you, Dr. Silver. We have Dave in Oklahoma asking, and this is a topic you spoke a little bit about in terms of talking to your doctor, but the question is, "What is the best way for the care partner to address the issue of sexuality? At a joint appointment or at an individual appointment?"

Sheila Silver, MA, DHS, ACS

I think it's a conversation that needs to happen between the couple themselves before it's brought up at a doctor's appointment. I think the partner should not be surprising the patient and bringing it up at a joint appointment. I think it's perfectly appropriate to bring it up in a joint appointment if there's been some conversation ahead of time so that the patient is aware that they have some questions.

And I think one of the best ways of doing that is by being vulnerable and speaking about this is what I've noticed has changed. This is the care partner, the spouse talking. I've noticed that something's different for us, and I'm wondering how to navigate it so that they're really asking for help for themselves instead of saying, "You know, this partner is having this kind of behavior that's a problem." That's sort of a blaming way of approaching that conversation. So, my suggestion is it could be brought up in an individual appointment if that's possible. But it could also be brought up ahead of time with the patient so that they know that they're going to approach that conversation of "I want some coaching" as your spouse of how to work with this. And so, I think either format is appropriate.

Stephanie Paul

Okay, terrific. So, a little bit more along these lines, Dustin from Washington is asking, "How do you recommend starting the conversation about intimacy with a partner who's not very receptive to this?"

Sheila Silver, MA, DHS, ACS

Ooh, great question. So, I guess my first question is, so, why aren't they receptive? Is it because of their own lack of interest? Is it they're struggling with desire on their own part? So that's a hard question to answer because if somebody's not interested, it all depends on why they're not interested in having the conversation. It may be that they're feeling ashamed or embarrassed about their body not responding appropriately and so they just don't want to get involved. Without knowing more about that situation, I would sort of encourage them to see someone who can help facilitate that kind of a conversation.

Stephanie Paul

Okay, terrific. It's all about communication, right?



Sheila Silver, MA, DHS, ACS

Yup.

Stephanie Paul

So, we have a question from Robert in New Hampshire, and he's asking, "How can you have sex normal again with the tremoring, stiffness, and muscle cramping of PD? I am very concerned about this, but my partner does not seem to be."

Sheila Silver, MA, DHS, ACS

So, the interesting part of that question that Robert's asking is he's wanting it to be normal again, and that's where there's some acceptance and some grief piece in it in that it's never going to go back to the way it was. So that's the hard part, and that's the real acceptance that we need to come at about a lot of things for us as we age and develop as humans is that we can't go back to the past necessarily. We can't reestablish it exactly the way it was. You need to create a new normal. You need to find a new chapter in your sexual experience. And if cramping or stiffness is part of what happens, when in your day is that least problematic; and making sure that you're trying to connect sexually or sensually at those times of day, looking at how your medications are helpful, and talking to your doctor about, "You know, I'm noticing that this is, all of this is really making an impact." And so, looking at, well, what is possible, even with the tremoring, even with the stiffness? What kind of touch would you like? What is possible and having a conversation with your partner about that.

Stephanie Paul

Okay, thank you. I think now we have someone who is calling in. We'd like to take the next question from the phone audience.

Operator

Thank you. Our first phone question comes from the line of Diane from Pennsylvania. Please go ahead.

Diane from Pennsylvania

Yes, thank you. Does Parkinson's affect a woman's ability to have an orgasm during sex?

Sheila Silver, MA, DHS, ACS

Yes. Because Parkinson's affects the entire nervous system, it affects orgasm as well. And so, it's not uncommon for women to struggle with getting to orgasm, just as it's not uncommon for men to get to orgasm. And so, they have to continue to keep looking at what are different ways of getting to orgasm for them. We can change our template of how we get to orgasm. Some women maybe who have never used a vibrator before find that's really helpful with aging, and it helps them find their way to



orgasm in different ways than they used to. But it's not uncommon for that to be an issue, and there's ways of working with that, especially if you can get some help.

Stephanie Paul

Okay, thank you, Dr. Silver. We have another question from Roger in Connecticut, and he is asking, "My question has to do with the fact that my voice has gotten very soft and sometimes inarticulate. This clearly has created problems in our usual communication. Any ideas about how to deal with this?"

Sheila Silver, MA, DHS, ACS

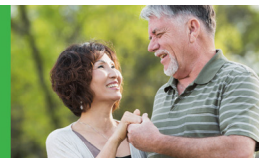
Yes, that's a great question, Roger. So that is a very common problem that affects emotional intimacy with couples; and what I sometimes have recommended in the past is that couples, because it can be frustrating to have conversations with a soft voice, I think that heart-sharing that I was referring to earlier in the program that's so important for that emotional intimacy can happen in other ways, maybe through writing. Like sometimes couples can create, like leaving each other notes or letters on their pillow or they can have a journal where they write how they're feeling about each other in a journal; and then the next person writes. And each day a different person writes or they each write something every couple of days. So, there's a way in which you can find other ways to share more of your heart that may be hard to do when you're just naturally speaking and you're forgetting how soft you are. Because I think continuing to share those things that you wish you could say, that sometimes you forget to say, this is really for everybody, but particularly if you're noticing that the softness of your voice makes communication problematic and frustrating for your partner, is just finding other ways around it. Finding other ways to communicate through notes and letters that can be really helpful. And also working with, I assume, working with a speech therapist, of course, to see if you can make a change in how soft your voice is. That could be really helpful.

Stephanie Paul

Okay, thank you. We have another question from the Web. This is James calling in from Georgia, and his question is, "Does spontaneous sex preclude the necessity of setting a specific time for a sexual experience? Will setting a time be more beneficial?"

Sheila Silver, MA, DHS, ACS

Well, there's nothing wrong with spontaneous sex. It's just couples need to look at how often is that happening. And setting a time may be more beneficial if it ensures that there's that opportunity that the couple's finding the time that they want to have some sort of physical closeness. So, I think it's, again, a conversation that a couple needs to have around how often are we being sexual. Does that work for both of us? Are there some ways we want to up our physical intimacy? Maybe not necessarily a full sexual experience, but we want to just be more naked together or touching each other a little bit more than we currently are. And so, I think couples need to just look at their pattern, how often is it happening, can they compromise on how often that happens, and can they take turns in terms of really planning that time and making it special and being on the same page about what



happens. And, again, having a sex therapist or sexologist help you with that conversation can often be really helpful.

Stephanie Paul

So, we have Pam calling in from Illinois, and she's asking, "Can you give more examples of what is bridging time and how to do that?"

Sheila Silver, MA, DHS, ACS

Oh, great. Sure, so bridging time is stopping what you're doing- So I think you might understand that much, and other examples of things that you can do during that time that are helpful for a lot of people is sometimes reading something erotic, having a bath or just shaving your legs, or putting on something that makes you feel more sexual or sensual. It could be a special scent that you save, like a little lotion or a perfume that you only put on when you're planning on being sensual with your partner. So, there's an aroma cue that happens for you.

Maybe it's taking a walk first before you do anything because you just sort of need to clear your head or sitting out in your garden and just sitting and not doing, but being. Because the whole point of that time is to help you transition into just being in your body. So, noticing am I hungry? Is there a way in which I'm not feeling very relaxed, and I need to just do a meditation or I need to just stretch a little bit or do a little bit of yoga? I mean it really could be almost anything.

But it could be something more sexual that sort of kind of gets those juices going, but it could be just, like we often are more sexual on vacation, I think. Some of it is just we're in a more relaxed frame of mind. So, bridging is sort of your little vacation before you're being sexual with someone, so looking at what that might be for you.

Stephanie Paul

That's very helpful. Thank you, Dr. Silver. I think we have a caller on the phone, so let's go to the telephone audience, please.

Operator

Our next telephone participant comes from the line of Tom from Pennsylvania. Please go ahead.

Tom from Pennsylvania

Yes, thank you. Sheila, I had a quick question. Does Parkinson disease cause sexual addiction or does it aid in its development?

Sheila Silver, MA, DHS, ACS

It does not cause sexual addiction. What it does is the medications, the dopamine agonists that patients, the treatment that some patients are on, often causes more addictive behavior; and that can



show up through gambling, shopping, eating, and hypersexuality. And so, it's the medication that's really causing it, and so it is something that definitely needs to be brought up with the doctor and looked at. And it's something that's very common, but it can be often worked with.

Sometimes people who feel that surge of more sexuality feelings don't want to change medications because it feels good. It helps them feel alive, so this can often be problematic with couples if somebody's wanting a lot of sexuality and the partner is not wanting as much. And working out that discrepancy and sometimes them not wanting to change their medications, that can be problematic. But it is something that, I think, definitely needs to be brought up in their session with their neurologist and potentially a social worker could be helpful.

Stephanie Paul

Okay, great. We have another question from a Web participant. This is Alexandra in South Carolina. And Alexandra's asking, "How do intimacy issues differ between men and women with PD? Where does self-image fit into this issue?"

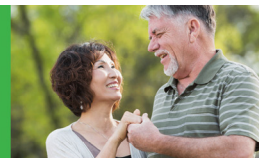
Sheila Silver, MA, DHS, ACS

So, I'm not sure that there really is a lot of difference between intimacy issues between men and women. I think at the end of the day both men and women want to be connected to their partner. They want to feel affirmed. They want to feel loved. They want to feel important. They want to feel like they matter. They want to feel like they're more than just their disease. And so, I think that is important to remember, and looking at what are those things that each person needs to feel those things. So that may be where men and women differ is what's going to help a male feel important is maybe different than what's going to help a female feel important.

And so, I think the self-esteem issues are also sometimes similar, but I think sometimes women are a little bit more critical of their bodies and their changing bodies; and so sometimes they are harder on themselves and bring that into a sexual relationship, and so that can be problematic. Even as just we age and our bodies get larger sometimes than we want them to be, I think it's important to realize that, at the end of the day, our partner wants somebody who's happy to be with them; and it matters less where the curves and wrinkles are, and it matters just more our interests and our openness to just giving pleasure and receiving pleasure. And so, I think sometimes it's not conversation that men need; but they, at the end of the day, want the same kinds of intimacy that women want.

Stephanie Paul

Okay, that's terrific advice. We have a question again from the Web. This is Thomas writing in from Mississippi. And his question is, "Do the movement issues of Parkinson's disease affect the sustainability of an erection? Any suggestions of ways to prolong an erection?"



Sheila Silver, MA, DHS, ACS

Well, the inability to maintain an erection is something that's very common with Parkinson's patients. And for some, something like Cialis or Viagra can be helpful for them. And so, yes, Parkinson's affects that; but I think it comes back to what I was speaking about earlier in terms of really sort of seeing sexuality as a more fluid thing. And erections are things that come and go, and arousal is something that comes and goes in any given sexual experience. And so, I think rather than if medication is helpful in sustaining an erection, great. But if it's not helpful and people are unable to do that, I think what's important for men to realize is that's not what defines you as a wonderful lover. You being present, you being open, you being interested in the other person's body, you being receptive to touch. I mean all of these things are who we are and what we bring to the table is so much more than just the function of our bodies. And so, I think men, as they age, need to let go of the importance of erection. Oftentimes they have no control over it. So being caught up with it just distracts them from their partner. So, I think just being really present with we're here right now. What do we want to do? Where are our bodies going and letting go of it having to look a particular way?

Stephanie Paul

Okay, great. Thank you, Dr. Silver. We have a question from Donna in Illinois, and her question is PD bladder issues make me hesitant to have intercourse. Any suggestions?

Sheila Silver, MA, DHS, ACS

Yes, so I think what you can do very easily is there are things that you can get, pads you can get. They're very, very thin at Walgreens or Rite Aid or your local pharmacy, that you can lay down that have sort of a plastic backing and can absorb fluid. And I would say put something like that down on a towel if that feels easier for you. But just trying to let it go and not worry about it. You empty your bladder before you're being sexual, and then if something comes out in the course of being sexual, it's going to be a fairly small amount. It may be that you're actually, women ejaculate a prostatic fluid when they orgasm sometimes; and it maybe it does come through the urethra. So, some women think that they're excreting urine when, in fact, they're excreting prostatic fluid. So, there's a piece about learning about female ejaculation that may be helpful.

But even if it is, in fact, urine, there's a way in which you can put something down and then just whisk it away when you need to. And it may be in the shower or in a bathtub that you're able to be sexual or other places that may make it easier as well.

Stephanie Paul

Okay, thank you. So, we have time for one more question today, and this comes from Jake who is in Texas. And the question is Parkinson's medications heighten my sex drive. How can this be balanced with the intimacy needs and interests of my partner?



Sheila Silver, MA, DHS, ACS

So, I think the idea of discrepant desire is something that's so common between couples, and certainly if Jake's on a dopamine agonist, he needs to look at how much has his sex drive changed. Is it dramatically different or is it just a little bit different? And, again, having a conversation with his partner and saying, "How can we work with this? Is this something a real medication change needs to happen or is there a way we can be physical more in a way that works that isn't problematic and doesn't have to look a particular way?"

So, I think it's a conversation that both has to happen with the doctor and potentially a social worker or a sex therapist could be helpful in trying to manage that different desire because it's the number one thing that I see in my office is that difference in desire and how to compromise and how to work with that, and the couple works with it in other areas. And so, it's a way of figuring out in this area how do we work with that in a way that works for both people.

Stephanie Paul

That's terrific. Thank you so much, Dr. Silver.



Closing Remarks

Stephanie Paul

[Slide 21] I want to thank everyone for participating in today's telephone and Web education program. I do apologize that we weren't able to get to all of the wonderful questions. But if you have a question and would like to speak to someone in our Scientific and Medical Affairs Department, **[Slide 22]** I encourage you to visit our website or call 1-800-223-2732 and you can ask your questions there.

I want to thank Dr. Silver for her presentation. I also want to emphasize to everyone on the phone that we really do appreciate your feedback and comments and want to make sure that you complete the program evaluation form.

APDA is so proud to invest in patient services and education and to have been a funding partner in most of the Parkinson's disease major scientific breakthroughs that are improving the quality of life today. To do all of this, we rely on the support of the entire Parkinson's community. If you are interested in supporting us and want to learn more about how you can get involved, please visit our website at apdaparkinson.org.

Our thanks, again, to Dr. Silver and to all of you for joining us today. We all agree that being informed about your disease and treatment options is the best way to empower yourself and take control of your care. Have a wonderful day.