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Speaker 1: Navigating Parkinson's disease can be challenging, but we are here to help. Welcome to The Michael J. Fox Foundation Podcast, tune in as we discuss what you should know today about Parkinson's research, living well with the disease, and the Foundation's mission to speed a cure. Free resources like this podcast are always available @michaeljfox.org.

Becca Miller: Welcome to another episode of The Michael J. Fox Foundation Parkinson's Podcast, I'm your guest host Becca Miller. I'm a licensed clinical psychologist and associate professor in the Department of Psychiatry in the Yale School of Medicine, and I was diagnosed with early onset Parkinson's disease in 2013 when I was 39. I'm also a member of The Michael J. Fox Foundation Patient Council, I currently am single and I live with my 11-year-old daughter and our very jumpy dog and two temperamental cats in New Haven Connecticut.

We're going to kick off today's conversation about navigating dating and romantic relationships in Parkinson's. So some of the things that we're going to cover are how dating can be hard even when you don't live with Parkinson's disease. And that being single in our Parkinson's community is fairly unique, most people are older, have care partners, but that dating as a person with Parkinson's comes with its own distinct considerations and experiences. So really, the experts on this topic are those who are living it, we're going to talk about it openly and frankly, we're going to talk about some of the things that we've learned, negotiating, dating and relationships, and we hope that even if you are in a committed relationship, some of the tips shared in this conversation could shed some light on your relationship.

Let's start by introducing our guest on today's podcast. Joining us from Salem Oregon, we have Steve Stryker and Susi Enderich. Steve and Susi have been dating since 2020, that's four years after Steve was diagnosed with Parkinson's in 2016 when he was in his fifties, and they got married in November, so congrats to Steve and Susi.

Steve Stryker: Thank you.

Susi Enderich: Thank you.

Becca Miller: And then from Vancouver Canada, we have Peter Jarvis, Peter is currently single and dating, and he was diagnosed with Parkinson's in 2017.

Peter Jarvis: Thanks, Becca.

Becca Miller: Thanks to the three of you for being here and sharing your thoughts on this topic. To start off with, let's take the people with Parkinson's, what were your main considerations when you first started dating as a person with Parkinson's?

Peter Jarvis: I think I'll start off, Becca, so thank you for the question. My considerations were exactly the same, I would guess, as anyone without Parkinson's, that I was looking for someone to pair up with and to share my life and share my achievements and trials and just be more whole entity. And I've only online dated once before, which was 10, 12 years ago, and it's just learn the platform, learn the norms of the platform and understand how to engage in a meaningful constructive way with your romantic prospects.

Becca Miller: Was there anything, Peter, for you in particular, that dating as a person with Parkinson's that felt different?

Peter Jarvis: Not really. What became quickly clear to me was, having Parkinson's is so central to my identity that if I felt any connection at all with the person I was meeting up with, that I have Parkinson's, I've always shared in person, never in a chat or a text. And if there was any connection at all, then I usually, when we were discussing something about me that I enjoyed about myself, I do improv, so I've got to tell you that it's a standard question, so tell me about improv, and that provides a really neutral segue into, "well, funny, I got into improv because I pursue it and perform it and practice it and teach it for cognitive health because I have Parkinson's," so I always give context.

Becca Miller: Right. And what kind of reactions did you get when you shared that?

Peter Jarvis: Almost universally, curiosity, interest, it's a very positive context in which to share that you've got a disease and a condition that actually interferes with your ability to live your life freely and without thinking.

Becca Miller: Mm-hmm. That's great. Steve, what about for you?

Steve Stryker: Interestingly enough, the considerations I had in the beginning, to set the table, after I was diagnosed, well, first, I was divorced from a long marriage, met someone, got remarried, was diagnosed, got divorced after a short marriage and I found myself in the dating scene. So psychologically you can imagine, I was licking my wounds and felt a little bit bad. And one thing I have to say is, I always thought of myself as a very self-confident person, and when you go out in the dating world, that is an asset generally. But after being diagnosed with Parkinson's, I became a lot more self-conscious, and I find myself not as confident and outgoing as I was prior. Now, some of that could just be aging, I've got three grown children, your lifestyle changes, et cetera, but before going out there, I thought a lot more about, how do I appear to others?

I can think back in my life, I'm relatively tall, I think before my fifties, I stood 6'6", 6'6" and a half, I might hunch over a little more now, but I can remember

when I was in the eighth grade and I started growing, my older sister saw me slouching and she's like, "Steven Stryker, you're going to be tall, be proud, stand up with your head up and your chest out," and so I always did that. And the way Parkinson's affects your posture, you start to hunch, and I feel like I'm constantly fighting that as just an example. And those physical attributes that filled me with confidence, I felt were slightly stripped away, and so the way I internally defined myself had to change, and so that presented a challenge.

And much like Peter, I went online, I can remember my youngest son was visiting me and he's like, "dad, you're twice divorced, I don't want you to be alone, we're going to get you online tonight." And I got on an app and started putting together a profile. And it's funny, in the dating world, and I'm sure you two have both seen how people try to put the perfect profile together to highlight the best things in the best way. I didn't do that, I picked a bunch of goofy pictures, Susi knows, and I had very little information about myself out there, I think compared to others, I just didn't put that much effort into it because I felt I'm a what you see is what you get kind of guy.

And then the routine typically on the dating apps is, you begin to chat with the people, and just like Peter, I would never say I had Parkinson's in the text format, I'd wait for a person to person. And typically, if I was on a date and I didn't feel there was a connection, I wouldn't even share it, they may have noticed something in gestures or in my movements or in my speech, but I wouldn't say anything. If I felt there was that connection and this would go into, even if it was a short-term relationship, I would share immediately.

Becca Miller:

Yeah, the issue of disclosure is such a big one, and I think that is something that, for myself, I don't put it on my profile or anything like that, but in person, I remember one time I was going to break up with someone actually and then I shared it. We'd only been on one date before and I was like, "well, I think I should tell you this, even though we're breaking up, but I hoped we would still be friends." But anyway, and it turned out that he had already Googled me and knew, which was such a shocking thing to me because I thought it was going to be this big deal to share it and then it turned out it's not at all. But Susi, I wonder from your perspective, what was that like hearing that from Steve for the first time?

Susi Enderich:

There's such a vivid memory to know because it was COVID time, we were both scared what other people would think about seeing someone when it was so dangerous. And I have a nursing background, so I felt really, really embarrassed, but when he walked through the door, we'd visited for a little bit and it didn't come out maybe until three, four hours into our visit and then the cat got into everything. And as I was trying to deal with the cat, he goes, "I have to tell you something," and I'm like, great, here we go, and I didn't know if it was like, see you, bye, and he decided to tell me that he had Parkinson's.

I knew what it was and understood it, but I did not realize the in depth symptoms to feelings, to looks, to breathing, I had never seen that. And the more I got to know him, there were some scary times and I didn't know what to do, but now I feel like I don't have to know what to do, I feel like, well, if he gets to where I think he can't drive, there's been times where he can't drive and he has a stick shift, and so I had to drive that home one day and stalled it like five times. And he goes, "you're not driving home, we got to find somebody to drive us home," but it turned out okay, I drove us home. But it's stuff like that, then I'm like, "my gosh, I don't know, I haven't driven the stick in a billion years and you're not feeling good," and now I'm right on top of the medicine, it goes in the car, it's in my drawer at work, I give his friend medicine to when they walk in case he forgets, so it's little things like that.

And I knew that he would have bad days, but I didn't know he'd have bad days, so I'm learning every day about signs and symptoms because you get depressed sometimes, I can tell when he feels depressed. Because he is home by himself all day long, he has a lot of projects, but when you're alone at home and you're shaking and you feel like crud, I don't know what that feels like, so I try to be mindful of it because unless you're completely into it and you have the disease, nobody ever knows what somebody else feels like.

Becca Miller: It sounds like, Susi, you feel like you're learning every day. Do you feel like there's something you wish you'd known about Parkinson's before starting to date Steve?

Susi Enderich: Not really, because I think that it wouldn't be natural almost because you just don't, well, let me just study, make sure you don't have this, this, and this, that's not what I was wanting. I wanted a partnership, I wanted someone like everybody wants, to share a life with somebody and enjoy that person, not focus on, "my gosh, you have that, what am I supposed to do now?" Life gives you those things and you just deal with them the way that you're handed them, for me.

I wouldn't call this dealing with, this is a commitment that I made not only to him, but to myself that I knew walking into this after he told me, because he gave me the honesty of telling me because he thought there was something there. And so from this date forward, I always take care of him as much as I can when I'm here.

Steve Stryker: Becca, what I find is, what's a real icebreaker when I out myself to them, I just say the big L in my forehead is for Levodopa.

Becca Miller: Nice. Peter, have you had some negative experiences at all?

Peter Jarvis: I can't say I have, post-date, I thought we had a great meeting, and then you get a text just saying, I didn't see the spark, or didn't feel the spark, or didn't this or didn't that. And as far as I'm concerned, I don't back them into a corner, I don't

ask why, I just say, "thanks, I enjoyed our time together and I hope you find the perfect person for you."

Becca Miller: Mm-hmm. That sounds about right. It's always hard to know with any dating what the reason is, and I don't know, there's so many different things that cannot click.

Steve Stryker: It's the big L in my forehead, I'm sure.

Peter Jarvis: Yeah.

Becca Miller: Steve, I want to go back to you and ask you, what were some of your hesitations or fears in sharing that with Susi?

Steve Stryker: Well, there's always that fear of rejection. And unlike Peter, I have this serious tone to myself because like Susi said, I put it, "Susi, there's something I need to tell you," and she thought I was getting ready to pack up and leave at that moment and say goodbye to that. But then I had that fear that she might actually say, "it was great meeting you, I don't have time for this in my life." And Peter, I love your attitude because that was always my attitude, there's so many people out there, if I'm not finding the one that I enjoy and enjoys me, I just keep moving, tomorrow's not a promise, enjoy today, enjoy the moment.

Peter Jarvis: Yeah, tomorrow's not a promise, you need to live your life today. Because the only thing we have control over is how we respond.

Steve Stryker: Yes.

Becca Miller: Yeah, so true. I had an interesting experience once where I was dating someone with a physical disability, not Parkinson's, but something else, and it was pretty interesting because when I shared with him my Parkinson's, it ended up ending the relationship because he couldn't handle that information about me. I think the idea of having two people with disabilities together was too much for him, actually. I knew about his disability because it very clearly manifest, but for him to find out for me, and so that was sad, but it's also, if that's something that he couldn't manage, then better to know now and move along.

Steve Stryker: Yeah.

Peter Jarvis: Yeah, I'm very much, let's get that business out of the way right up front and then we can either move on to engage further and develop a relationship and see where it goes and experience the joy and fun of it. If Parkinson's is a big deal for you, then we're just better off not going any further.

Becca Miller: Mm-hmm. What kinds of advice would you offer to other people with Parkinson's who are single and dating?

Steve Stryker: Well, the first thing I think, and all of us probably are aware, if you're taking medication, try to time it so that when you go out on that date, things are meshing because we all know what it's like when all of a sudden it's ebbing or it just comes to a complete stop.

Peter Jarvis: I've had the experience where I showed up for a first date and I'd forgotten my meds and I was coming right up to my medication point, and suffice it to say, things didn't progress well.

Becca Miller: Yeah, the med timing is quite a thing to try and manage.

Peter Jarvis: Even if you have to top up with a little half dose of meds just to make sure that everything's stable and all the wheels are greased.

Becca Miller: Mm-hmm.

Steve Stryker: Yeah.

Peter Jarvis: The other thing I'd say is, try and have fun, because it's a journey of inquiry and it's a journey where you're seeking connection. And part and parcel of that is, think of some segue lines so that you're not caught flat-footed and just do the fish out of water thing because that's just not an attractive look for anybody.

Becca Miller: That's such a good point. So maybe having some handy little clips in your pocket, like the elf on your forehead, Peter, or?

Peter Jarvis: My favorite segue to outing myself as being a parky is, "improv, that's really neat, how did you get involved in improv?" And it's a perfect natural extension of that offer to respond by saying, "well, funny you should ask because."

Becca Miller: Susi, I wonder for you, did you notice any of Steve's symptoms before he shared with you his diagnosis?

Susi Enderich: Yeah, there was one in particular moment, he had to go to the bathroom, and so all of a sudden he's in there for a while, and then he is knocking down all my stuff off the walls. Because I think he got dizzy, and so I'm like, do I knock, or? I probably should go check on him, that would probably be the smart thing to do. So I knock on the door, I'm like, "are you okay?" He goes, "yeah," I go in there and my stuff's all over the place, I'm like, "what were you looking for?"

Steve Stryker: I wasn't looking for anything, my shoulders rubbed the wall.

Peter Jarvis: No, Susi, you said, "Steve, do I know you well enough for this?"

Susi Enderich: It's like the litter box was tipped over, almost litter was coming out everywhere, I'm like, my gosh, I thought he got dizzy. And then after I'm dealing with a cat and him trying to bother us, then he sat down and I noticed he had his little pill

box or his little pill thing on his keychain, and I heard something squeak, the awful squeak that had, and then, "I have to tell you something," I'm like, "what's happening?"

Becca Miller: Is this right before, Steve, you shared with Susi about your diagnosis?

Steve Stryker: Yeah, I took a dose because I was feeling symptomatic. One of the symptoms I have, and I don't know if either of you ever run into this, when my medication's wearing off, if I have to do something that requires fine motor skills, I have a sudden urge to go to the bathroom, and it might just be a trickle, it is a pain in my backside because-

Peter Jarvis: It's a pain in your front side, Steve.

Steve Stryker: ... Yeah, you are right, it is. But that's what happened at Susi's house, I don't know what I was trying to do, whether I was trying to eat in a nice, neat, and fashionable way and my medication was wearing off, and all of a sudden I'm holding the fork trying to be swabbed, and I got to go to the bathroom like this, and it's very urgent, but then not much comes out. But I managed to knock the lid off the litter box, she had this decorative little ladder I knocked off the wall.

Susi Enderich: You remember the ladder?

Steve Stryker: Because one of the things I noticed when I first got diagnosed, I've been active most of my adult life, worked out, played a lot of basketball, but I kept rubbing into walls with my shoulders, I think it was my way to guide my way down the hallway or whatever. So anything that's hanging up, like Susi had me put up some floating shelves, I have to put them in places where I know I'm not going to bump into them.

Becca Miller: Yeah, I imagine your height doesn't help with that either.

Steve Stryker: Yes.

Susi Enderich: He bumps his head all the time on the hood of the stove.

Becca Miller: That sounds like quite the commotion to have happen during a date.

Steve Stryker: Yes.

Becca Miller: I'm impressed to both of you that you worked your way through that, and that sounds like it's a pretty happy memory, also one of those stories to tell.

Steve Stryker: Yeah. So in some way, I'm here to tell people, don't be your perfect self, be yourself because that's who you are.

Peter Jarvis: Yeah, I'd echo that, Steve, you need to own the fact you're a parky because it's so integral to everything we are and everything that is about us.

Steve Stryker: Can I ask you both a question? Have either of you ever dated someone that knew all about Parkinson's, so when you disclosed it, they?

Becca Miller: I haven't, not so much, some folks have known a little bit about it, but never someone who's really knowledgeable, I think that would be an interesting thing to have happen.

Peter Jarvis: I've dated a couple of people that knew a lot about Parkinson's because they had an aunt they were very close to or a father or a relative, and so they were quite knowledgeable. And that in and of itself formed a great basis for further conversation because you can then talk about how every Parky has a unique set of symptoms and circumstances, and this is what's unique about me and the issues and things that I really have to stay on top of.

Steve Stryker: I'd never have had that experience, but I was just curious. Susi being in nursing, she had some familiarity, and I think the other thing that's unique about her, she's very empathetic, she could tell just by looking at my eyes, if she saw any remote distance in them, she'd be like, "your medication's wearing off, you need to get to it." Now we've been together for four years, she can hear me breathe and she's like, "your medication's wearing off, you need to take you dose."

Becca Miller: What's that like for you, Susi?

Susi Enderich: I don't know, it's almost like I have a timer inside of me that just knows, he could be upstairs, and I'm like, I got to run upstairs. Because sometimes lately, he has been bad, he'll sit there and suffer and I'm like, "are you kidding me?" And so I put a bottle of medicine upstairs and there's no excuse now.

Steve Stryker: But just to clear the air, and I don't know, Becca, or Peter, if either of you ever feel you get a little bit of dyskinesia, uncontrolled movement, you want to slow down, I just want to feel like I can sit in my seat? And so there are times where if I'm too dosed up, I can't stop moving, you've seen that, especially when I watch football, if I stand up, I'm just gyrating to the game.

Susi Enderich: Or when he drives, I notice it's getting worse, I'm like, my God, and it scares me that he's going to not be able to drive.

Steve Stryker: It scares me as well.

Susi Enderich: But I think with a stick shift, he's more able to control the movement because he has something to do and he is using his brain with it.

Becca Miller: When he's driving with stick?



Susi Enderich: To help the dyskinesia as opposed to the other car, Hoover, it's just automatic.

Steve Stryker: Yeah, it's actually easier to drive the stick shift.

Peter Jarvis: Because I drive a stick as well, and what I find is, it's a measure of where I'm sitting at in the medication cycle with how fluently I can use the clutch.

Steve Stryker: Yes. So if you're a passenger in my car and my medication's wearing off, you might be a little bit of this back and forth, jerky.

Peter Jarvis: Driver induced dyskinesia.

Susi Enderich: Or a sick passenger.

Becca Miller: Susi, I wondered what advice you have for people with Parkinson's and dating?

Susi Enderich: One, be yourself and let things happen naturally and know that, I am who I am and I am a special person and I love myself. And that's the biggest thing, is love yourself because nobody else is going to do it for you like you can. And I think that with trying to get to know somebody, I don't have it, obviously, but you'll just know when you find that person that has that empathy, the caring and wanting to be able to help you with when you have a bad day with your medicines or just a bad day in general, because we all have bad days and we don't even have to have Parkinson's or whatever. But I believe there's somebody out there for everybody, and when you're looking sometimes, I think you don't find it.

Becca Miller: There's that phrase, there's a lid for every pot, right?

Susi Enderich: Yeah. Because I feel like for myself and my relationships, at some point, I was looking all the time and I was so desperate that I couldn't even love myself because it was a poor me story all the time for me, and I had to knock myself out of that because it wasn't healthy one. And why would you want to bring that into a relationship? And sometimes it does work when you're looking for someone, and that's great too, but I think that self-care and that person's going to know.

Becca Miller: That's such a good point. I think that's for me too, is there's always going to be something that you can worry about or be concerned about, and Parkinson's can be one of them, but I think just trusting in the process that you'll find someone and that the relationship will come back. But that's what makes me so happy about having Steve and Susi on this podcast and not just having single folks, but showing that it is possible to find love in a relationship after the diagnosis.

Susi Enderich: Yes, absolutely.

Steve Stryker: Yes, I feel so blessed.

Peter Jarvis: Becca, the only other thing I'd like to add in that subject is be patient, when you're establishing a basis for relationship, take your time to text back and forth to just explore and don't try and answer every question every time, it's the dance of the seven veils. And so you want to just gently and gradually work into becoming more knowledgeable and curious about the other person so that you have a basis for a relationship when you've made that initial determination. Because the first is, do you left swipe or right swipe if you are using an app? And then secondly, do you build a basis for relationship and engagement? Are they curious? Are they interested in you for who you are and not the fact that you're a parky or not?

Becca Miller: And I think then too, it's being interested in the other person too, and not just focused on the Parkinson's to make sure that it's a reciprocal kind of thing. What have you found for apps or other platforms or resources in your process?

Peter Jarvis: I'm using Bumble right now, I used e-Harmony 10 years ago.

Steve Stryker: And Susi and I met on Bumble. But you talk about swiping left and right, Susi claims to this day she accidentally swiped right, I don't believe.

Susi Enderich: Well, I was sitting in bed that morning and I'm like, well, because my friend made me get on this and just put a profile on there, it wasn't even my name. I went under Elizabeth, which is my daughter, and so she put me under Elizabeth and I went on one date and that was horrifying, and I was like, I'm just done with this, I don't want to do it anymore. And then this little bald headed man with a green lucky shirt and dinghy balls for March for St. Patrick's Day and he is Irish came up and I'm like, what is this, I'm so done, and then I'm like, it went right and it's a match and I go, "no."

Steve Stryker: Then she texts me at like 5:30 in the morning and I'm up, so I answer, and then the rest is history.

Susi Enderich: We talked until midnight that night.

Steve Stryker: Yeah, I burnt my chicken that day, we got a lot of memories.

Becca Miller: That's awesome. So it was total luck, it was almost, Susi, like you had a perky moment when you-

Susi Enderich: Apparently.

Becca Miller: ... Swiped the wrong way, that's great.

Peter Jarvis: It just reminds me that what the universe has in store for us, it will not let pass us by.

Steve Stryker: That is 100% right, even if you try to ignore it.

Becca Miller: That's awesome. So I wonder if there are any other funny stories that either any of you have from dating or from ... I think that having a sense of humor about all of this is so important just in terms of the things that can happen as a parky.

Peter Jarvis: You just have to laugh at what the universe delivers to you and try and have fun and enjoy the experience.

Steve Stryker: Yeah. And the other thing, and I always comment to Susi about it is, for some reason, since I've been diagnosed, I have a lot more trouble keeping food in my mouth, and when you're out dating, if you're having a meal, that can be quite embarrassing because people judge you for that. But we manage, like you said, Peter, I just make a joke out of it.

Peter Jarvis: You need a dog.

Becca Miller: Yeah, that's why I got a dog.

Steve Stryker: We have one now.

Becca Miller: That's what I just was going to say.

Steve Stryker: That's exactly what Susi says.

Susi Enderich: He goes, "I'm a little messy at the table," I go, "get a dog, Steve."

Steve Stryker: We have one.

Susi Enderich: Now we have one that eats everything.

Peter Jarvis: What's it called, Hoover?

Steve Stryker: His name is Fred, but yeah, he is a Hoover.

Becca Miller: I want to just speak to, Steve, you were saying earlier about the lack of self-confidence, I experienced that too when first dating with Parkinson's, and then I realized it was something that half the time it was that I wasn't interested in the person, it wasn't necessarily that. So it can go either way, and it was an important lesson for me to learn that it wasn't just about me feeling one down because I had Parkinson's all of a sudden, but that actually I was just figuring out if I actually liked the person and wanted to continue on with the relationship.

Peter Jarvis: Yeah, that's another thing with texting and chatting back and forth, is again, you form the basis of relationship because if you're not interested in them or they're not interested in you, just chop it off at the knees and move on, because the one thing we never get any more of is time.

Steve Stryker: True.

Becca Miller: Yeah, that's definitely something that having Parkinson's has brought home for me, is make the most of it while you can. Well, this has been such a great conversation, again, a big congratulations to Steve and Susi who got married in November, yes?

Steve Stryker: Yes, November 1st.

Becca Miller: Fantastic.

Peter Jarvis: Well done.

Becca Miller: Thanks to our panel, thanks, Peter, thanks, Steve, thanks, Susi.

Steve Stryker: Thank you for having us.

Peter Jarvis: Thanks for having me, Becca.

Susi Enderich: Thank you, Becca, thanks for hosting.

Becca Miller: It was a great conversation, you can find resources and links in our show notes, and please rate and review this podcast. Until next time, I'm Becca Miller, thanks for listening.

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