

Steve Iseman – Bonus Episode Transcript

Steve Iseman 37:05

[mellow electronic music] My name is Steve Iseman. I have Parkinson's. I've had Parkinson's for almost 11 years now, and I love exercise.

I'm married. I have two boys, aged 22 and 24. I have a very supportive community around me to help me with my Parkinson's. Really, so far, I don't have to lean or rely on anybody too much, but it's good to know that they're there, you know, when the time comes.

I started experiencing symptoms about 11 years ago. They were very modest to begin with. You know, I was having some difficulty typing and I talked to a doctor about it, which is, frankly, uncharacteristic for me to even bother dealing with these sorts of things. And it was suggested that I see a neurologist, and the neurologist, within less than a minute of working with me, said, "Yeah, you have Parkinson's."

I think, like many people in my situation, I'd come out of the doctor's office with a diagnosis that I didn't like, and I just didn't feel like talking about it, and I sort of followed that course for five years of not talking about it and that meant not telling almost anybody, including friends and family. And, I wouldn't do that in retrospect. It was a lonely time. You're sort of lying to your friends and family when you don't tell them something that's so important to you.

But something snapped me out of it. I attended a charitable event to raise funds for Parkinson's research and it was a cycling event, and I noticed that I was one of the only people there with Parkinson's, and what I had been reading and hearing about was just how beneficial exercise was, and frankly, cycling, in specific, so it drove me crazy. So, I resolved that the next year I was going to try to empanel a team of people with Parkinson's to join me at this event. I gave myself liberty to talk about it. I started telling everybody, [chuckles lightly] and part of my inspiration was I felt that there were lots of people like me who were either hiding or disconnected or not part of a community and certainly not part of an exercise program and, you know, I really wanted to gather as many of these voices together, first, to convince them to be more athletic, but also to help advocate for Parkinson's interest. Our voice is too mute on this point right now and we're being overlooked with regards to funding resources and, you know, any role I can play to help with that is, I think, useful.

I started approaching exercise as, you know, my daily obligation. It became my medicine cabinet and the benefit that I get out of it is so obvious to me and I know this, on occasions, when I have to stop for one reason or another. I'll give an example of this: two years ago, I did a very long bike ride that was three months of constant motion, and I was feeling just wonderful during that time – so wonderful, in fact, I said, "Hey, I wonder if I can go med free." So, I tried it one day and it was a horrible failure but, you know, it does underscore that I was feeling good.

[music continues] When the three months were over, travelling back home and dealing with obligations had me off the bike for about two weeks and my symptoms came back pretty strong. It felt like withdrawal. I got myself back on the bike, back into a daily routine, and I righted the ship.

There's also a cognitive aspect to Parkinson's and it's one of my chief complaints. I had a couple of tests over the years and it's, incredibly, showing progress, not degradation. And what else can I attribute that to than regular exercise? [music fades out]

[gentle electronic music] In 2022, we rode across Canada from Victoria to St. John's, Newfoundland. My friend, Jim Redmond, and I were cyclists and we had the two other friends who helped take care of logistics, and we were on a mission. The motivating force was to spread awareness of Parkinson's, but not generally to the public, although we did that incidentally. We were specifically looking for people with Parkinson's because, by my estimation, three out of four of them are disconnected from a Parkinson's community or support groups and a good number of them from any contact with the people or services that can assist them with their Parkinson's journey.

So, how do you find them? You know, they're not on any list, so we determined that the only way really to find them was to dress ourselves in shirts that said who we were and what we were doing, have a big RV behind us with signs saying, "Come talk to us," and we found people everywhere. People were approaching us to ask a little bit about what we were doing, and so often, in fact, it was getting to be daily, within 20 seconds of talking to them, they'd be in tears recounting their story or a story of a friend or relative. Crushingly, many of them would say, "You're the first person that I've been able to talk to with Parkinson's." [music fades out]

It felt really good to be there at the right time because we could encourage them to connect with people and we knew who and how to connect with. We'd facilitate that. But what I discovered was that these people wanted to be found. [glitchy electronic music] They'd walked out of the doctor's office one day with a bad diagnosis, and they clammed up, but it wasn't a decision, and giving them this opportunity to talk about it seemed to be pretty cathartic for them.... and, frankly, for us, too.

The thing that stops people with Parkinson's, by my estimate, is, one, fear. I think that people walk out of their diagnosis a different person than they were, walking in. Even though they've probably lived with their condition for 10 or 15 years before their diagnosis, they, all of a sudden, feel vulnerable or weak or afflicted, even though nothing has changed on that day; they're still the same person. The only thing that has actually changed is that the need for exercise has increased.

And one thing that I think is really important is, at that diagnosis, when they're having a heart-to-heart conversation with their neurologist, it would be so helpful if the neurologist was pointing them on a path towards fitness and exercise. [music fades out] And the next level above that is to say, "Oh, and here's some people that can help you on this journey," and to that extent, in the GTA—Greater Toronto Area—myself and a friend created a cycling club that we call the Rigid Riders and the notion is just that – if you're prepared to try getting on a bike, then we want to ride with you.

[light, bubbly electronic music] How Parkinson's has affected me, I probably wouldn't begin with physical symptoms. I would probably tell you that it has given me some direction and purpose with what I want to do with my life. I feel actually quite lucky. I'm working hard at this fitness but I think that I'm not only holding off symptoms; I think that I'm getting better. I'm improving.

I'm so convinced that this is beneficial to others that it gets me to shake off an introverted personality and actually go out and find people and talk with them and encourage them, which I find myself doing on an almost daily basis now. When I meet people who are newly diagnosed, I like to get a sense of where their head's at, and I do that by asking them a very bizarre question. I ask them how Parkinson's has improved their life, and a number of people, predictably, will think that's a ridiculous question. It's done nothing good for them and they recognize, okay, they're still adapting, they're still getting used to this diagnosis. A lot of people will say, "Huh, improved my life... Let me think about that." And that flags for me that they're in transition. They're moving into themselves 2.0, and a surprisingly large number of

people will respond to that question, saying, "Well, I'll tell you how it's improved my life..." and rattle off a couple of things. And that's my new best friend. [music fades out]

[upbeat electronic music] I am a better cyclist than I've ever been. I have a lot more focus in my life about what I want to do. I have a timetable now because there's things I want to get done. You know, I'm very hopeful for a cure for alleviating therapies but I don't want to put all my eggs in that basket. I am eager to get things done now. So, I don't have a bucket list anymore. I just have a to-do. [music fades out]

In the summers, I actually have five cycling clubs that I ride with and I sort of vary between them. One club has me getting up at 4:30am so that I can ride out and meet them up the north part of the city or 6 or 6:30am and then we bomb around in the dark for maybe two hours, and then I go home and everybody's asleep in my house. Often, I'll then follow that up with the second bike ride at home, using a trainer. If I only do that in the day, frankly, I'm set. When I cycle, I have to admit I go all in. If I'm on a bike, I'm doing my maximum, and I find it gives me energy and, frankly, license to do playful things. [music fades out]

I just got off the ski hill. There was a period when I had lost the ability to ski and cycle. With skiing, I lost the ability to turn left, which you really need [chuckles lightly], and with cycling, my legs were spinning in different shapes. I had one that, dutifully, did the circle it was supposed to, and the other one would spin triangles or other shapes, and it became a chore and not pleasant. But I had the amazing fortune of being paired with a movement disorder specialist who got me—Dr Kalia—and knew how important this was going to be in my life, even though I had already almost written it off. She said, "No, let's get you back to that," and, boy, it saved my life.

When I met Dr Kalia, she asked how I was and, being male, I said, "Oh, I'm fine." But she didn't leave it at that. She asked me about my athletics and things that were important to me and I mentioned the skiing and cycling. She said, "How's it going?" and I said, "Frankly, not that well." So, we talked about maybe things that I could do to improve it and that included medication. Now, I did not want to take medication. I had it in my head that things weren't so bad now, and I should hold off as long as I could because I didn't want the effectiveness of the medication to decrease when I would need it, when I was more elderly. She said, "Well, that's not really the way it works." And I said, "Oh, well. I don't know." She says, "Oh, you don't believe me, do you? Look. Let me put it this way. If you could have 10 great years, do you want them now or when you're an old man?" I said, "That's pretty convincing." [music fades out]

Those were the right words at the right time and they really changed the course of my life. Exercise is the thing that keeps the spring in my legs, keeps the speed in my muscles and, frankly, the smile on my face. [gentle electronic music] When I am cycling and I am giving it all I got, I must look ridiculous to people, but in my mind, I'm not cycling for today – I'm cycling for tomorrow. I want there to be a tomorrow, and I want to go even faster tomorrow. So, that means I have to work really hard today.

That means two things: one, I'm getting the physical benefit of the exercise, but in my heart, I am fighting. I'm pushing back against this illness. I'm not letting it take without a fight and, from the spirit, I feel fulfilled, and advancing both your spirit and your musculature are just so essential for the years ahead. You need them both. [music fades out]

[bubbly electronic music] If you have Parkinson's, you need a community around you. If you don't know that you need a community around you, you do. There's only so much that doctors and researchers

really know about this illness right now. There's more and more learned every day, but there's more questions, I think, than there are answers. In my experience, the best daily life hack comes from my friends in the community. Don't deprive yourself of that resource; it can really improve your life.

If you are the loved one of somebody with Parkinson's, this disease is trying to make them fade away. Whether it robs you of your dignity or integrity, your sense of balance or stability, whatever, a thousand cuts, it's trying to diminish them, minimize them. They need encouragement, not just somebody to cut their steak; they need somebody who knows when to say, "No, you do it. You continue to do it. I know you can do it so I'm going to let you struggle a little bit." Let them struggle. You'll develop an instinct of when your assistance is required or not, but know that there's a battle going on in them and they need help with the battle. They need you to come to their assistance, to encourage them to get out, to get active, and if you need help with this, find me or anybody like me who will be more than happy to help you with the task. [music continues then fades out]