

Hugh Johnston – transcript

Hugh 02:51

Hi, my name is Hugh Johnston and I've been living with Parkinson's, probably active in treat clinically for over five years now but the prodrome all the way back to the mid 90s but the first symptoms started in the mid 90s. My symptoms started with, with stuff that is associated with Parkinson's, like like sort of Seborrheic Dermatitis. That was probably the first one, then dystonia in my toes. That was fairly early on, like an anxiety disorder, which is very common in Parkinson's disease. That was maybe 18 years ago. Fatigue, which is a big, big problem in Parkinson's disease. I would have gait disorder, I would trip that goes all the way back to boy, a Europe trip, maybe 10 years. And eventually, after a head trauma, my toes started to shake, my foot started to shake. And then my arm started to shake and on we went from there Yeah, what happened was I got thrown into the roof of a sailboat and I hit on the back of my head, where your visual system and your cerebellum are. And it seemed to unmask a new symptom, which was this tremor that came with this Parkinson syndrome that I had been developing for years. Well, if you want to create an anxiety disorder, my diagnosis was a great way to do it. Although I already had one, so I didn't need any more.

Hugh 06:55

I got my actual diagnosis about two years after I started shaking. And it was traumatic. My reaction wasn't good. My doctor was, I was probably one of his last patients, he retired a week after. And he basically said, "You've got Parkinson's, you got bad luck. Go away, you don't need any meds yet." And that was that. And so I had nothing. So I had to go to my family doctor, and send a referral into Toronto Western. And then I went on a journey of researching, because that's who I am. And so the way I reacted, was to get busy doing something about it. And that's how I ended up meeting all sorts of advocates and some of the best clinicians and researchers in the world in Parkinson's disease here at Toronto Western.

Hugh 09:01

It had quite an impact on my relationships and my family, in the beginning. It's disturbing for people to see you when you're trembling. They don't know what to make of it. I went on this research journey. So we tried to see if it was medication induced. And so that whole conversation made people uncomfortable. But what it did do was it got me involved with advocacy. And it got me involved with meeting people I'd never met before and I reached out to, oh boy, a couple of leading advocates in the world, one of which is from Toronto. And you know what? They had a coffee with me right away. And it was amazing. And then I met Soania Mathur at a conference that I went to, and some of the most wonderful, leading edge researchers and clinicians in the field at that conference that was run by Toronto Western, and it's changed my life. Primarily, the big difference is I feel like I'm doing something about it about it, this Parkinson's disease that I have. And it gave me a renewed sense of purpose, which I didn't really have after retiring. The relationships that I've been able to build since then, have been fantastic and it changed my life by allowing me to express a lot of what I brought from my business career, in a setting of patient engagement with the researchers and with the clinicians and

staff, by applying those skills to help them come together to get better communication and education to the patients at Toronto Western. When the opportunity came up to be on the patient advisory board at Toronto Western, and then to be asked to be the first Chair, my role primarily, was to let people see how high up is up, as opposed to imposing anything on them. My former life allowed me to help them to get the best out of themselves, which is what I used to do.

Hugh 13:37

I've been on a number of patient advisory boards, I've been on a cup, very few where you don't get hurt. But I've been on only one where they actually do something about it. And many of them are very engaging and staff and faculty get it and understand and want to hear the patient voice, but they don't know how to make change for the better for the patients and for the clinicians and staff as well, based on what they hear. This Board is somewhat unique in its ability to actually get things done that matter. And there's two pieces to that secret sauce. One is the clinicians themselves nominated people for this Board because they trusted them. Because they trusted them and they knew something about them beforehand, they were well curated, but also they trusted them enough to take what they're told at face value and believe what they're told. The other magical piece is, they pretty much don't ask a question unless they plan to do something with it, and that's very unique. Most patient advisory boards get stuck in process and pomp and circumstance and the whole, making sure the structure is all there. And, the organization becomes afraid of, you know, what could these people that do, because they really don't understand how the organization works. And as a result, what they have to say, their solutions don't work. And that is true. But what they do know is they do know what's not working. And if you use those facts to show people like I used to do in my career, they can then figure out what to do to make it different and better, because it's the clinicians and staff who understand how it works, and are the only ones who can make it different and better.

Hugh 16:15

I spend a fair amount of my time with my family, I do a bit of sailing, I spend a fair amount of time doing what my uncle said to me one day, when I was frustrated, and I couldn't figure out what to do in a situation. He said, 'Just go help somebody and you'll feel better.' And so I do a fair smattering of that. And, I do a lot of napping [laughs]. Everything takes longer when you're retired, because you actually have the time. And so, being with good people, being good people. And trying your best just to be with other people so that you can do things that matter through people. Because on your own, there's very little you can do yourself. It's the synergy of getting good people together who share values, to have a share a common goal. And then it's just wonderful when you actually get there. It is really something else.

What I want people to know is, when they hear this term, you've seen one Parkinson's patient, you've seen one Parkinson's patient. That's not really quite true. There are many, many Parkinson's patients who are just like me. But there are many, many more who are not just like me, there are very many different kinds of Parkinson's disease. And I'll give you an example. If I said to you, my friend has cardiovascular disease, they might have any number of different conditions underneath cardiovascular disease that are very different. Someone might have vascular Parkinsonism, for example. That's part of cardiovascular disease, who knew? That's what George Bush Sr. had. And so there's very many different kinds. And there's kinds that are very kind to the patients like the one I have, which is very

lucky. And there's kinds that are not very kind to the patients at all, and are very aggressive and are boy, they're just... They don't know how to find a word that says that they just bowl the families over. Like, we even have a type of Parkinson's, that you could put in the same bucket as traumatic, and just as bad as Lou Gehrig's disease. And so everything in between, and for the patients, and the families and the care partners. It's doing the best you can with the type of Parkinson's that you get. And I've heard wonderful stories about people and how they live full and engaged lives, whether they're on the easy side, like me, or on the most aggressive side, like a friend of mine, who I met through the Board, whose mother had a wonderful life through four years of a very aggressive form of Parkinson's, and then got an extra two years, because she was brave enough to be completely disabled, and take the treatments that would extend her life. And it was just the most heartwarming story about how people, who decide to engage with life, and advocacy is one way to do that, is to just jump in and do something. And if you do, life will be good to you. Because you know what Heather, none of us are getting out of here alive. So might as well enjoy it.

So my message to people who have just gotten a Parkinson's diagnosis, and perhaps haven't had any contact yet with a movement disorders specialist, and are wondering about, 'What does this mean for me? Am I going to die young? What's going to happen to my family? Is this going to affect my work if I'm still working?' And the answer is, you're not going to know until it comes. And it will affect you often, as much as you let it affect you. A disability is a disability, it's not your life, whether your disability is Parkinsonism, or your disability is some form of paraplegia, it's the same, you get to choose very much. You can lead a very, very full life if you choose to do that.