

ONE DIAGNOSIS, FOUR JOURNEYS

Written By Cherlene Magnuson

"Don't even think about it. Do it! I always maintain a positive attitude in life and in everything I do."

Curtis P.

Here at Parkinson Association of Alberta, our very first contact with people typically happens in one of two ways: either they or a loved one has been newly diagnosed with Parkinson disease; or they (or a loved one) have had Parkinson's for a while and they are looking for resources and support. Regardless of the reason, we are always happy that they found us. At that first meeting, we often start with the basics to establish a foundation of knowledge and because we all know that "Dr. Google" can lead us down rabbit holes that are not always pleasant or factual. One of the visuals we use to describe Parkinson's is a tiger. The reason we chose that image is simple; no two tigers have the same stripes. Likewise, no two people living with Parkinson's will ever experience the disease in the exact same way. There are too many variables - progression, age, geography, personal approaches to health and wellness, the list goes on and on. So, while a tiger is still a tiger in

the grand scheme of things, each is unique as an individual. Over the past few months, I have had the extreme privilege to speak with several members of our Parkinson's community. Their stories are remarkably different but uniquely bound together.

Curtis P. recalls his first symptom being a slight tremor in his left hand. He sought medical advice at once, hoping it was something



Curtis P.

else, but when two neurologists independently confirmed Parkinson disease, his fear became a reality. And so, at the age of 49, Curtis was diagnosed with Young Onset Parkinson disease. Like many people diagnosed with Young Onset Parkinson's, the news came as a complete surprise. "Shock, actually," Curtis told me. "I was in denial, to be honest with you. And then I went into a full-blown panic attack. Like, what the hell? I'm too young. So, I didn't take it very well."

What struck me most about Curtis was not his age at diagnosis - but how he responded to it. Today, Curtis is one of the strongest advocates I know for exercise, research participation, and Deep Brain Stimulation (DBS). In fact, he recently shared that he has been selected as one of the first patients in Edmonton to receive Adaptive DBS technology. "The other thing I'm looking forward to, that's on a positive note, is the research," he said. "I participate in every single research study that comes my way."

When I asked what advice, he would give to someone considering DBS surgery, he didn't miss a beat:

"Don't even think about it. Do it! I always maintain a positive attitude in life and in everything I do. I'm just trying to keep myself busy. You don't want to sit and mope around. I think that stress will kill you and sitting around doing nothing will kill you."

Knowing positivity is an excellent skill/tool, but that it is sometimes hard to keep up; I asked Curtis what worried him and how he deals with tough days.

"My biggest worry?... The future, how it's going to play out. I live by myself," he shared. So, he has had to learn to make adjustments and build a network around himself. His son checks in daily. His medical information is programmed into his phone. And he surrounds himself with people through boxing classes, physiotherapy, friendships, fitness programs online and three different online support groups. "That's why I like going out to all these different things. Like boxing. I know if something happens, I'm surrounded by people." For Curtis there are three core truths: 1) community is essential, 2) exercise is equally as important as his medicine, and 3) Parkinson's is something to share, not hide from. "I was trying to hide it a bit, but eventually I embraced it."

Margaret M.'s Parkinson's story began in a way few of us could ever imagine. I had asked Margaret: "So how did you manage the news that you had Parkinson's? "That's an interesting question because the day before I was diagnosed with Parkinson's, I had been diagnosed with breast cancer," she said. "So, it didn't really sink in until I would say probably three or four months later, that I had Parkinson's." She was too busy fighting another battle. Months later, the reality of Parkinson's began to settle in. "It was something that was progressive and incurable. Something that I had to manage. I had spent the interim dealing with breast cancer because to my way of thinking, it was more important."

Margaret never hid her diagnosis.



Margaret M.

"No. I don't hide things like that. To me, that just causes more anxiety, more stress, more issues going down the road." In fact, she actively invites conversations. "I proudly wear t-shirts with funny or impactful statements/designs that might get people to ask me questions

about it (Parkinson's) so I can educate." One of her favorite t-Shirts says "No Balance" on the front in the same font as a popular show brand logo. When I asked whether people treated her differently after learning about her diagnosis, her answer was immediate. "No. I think it's because I'm so open about it."

Margaret also lives alone, and like other solo individuals living with Parkinson's, she has had to develop systems and develop support networks for herself. "Being solo means, you have a lot more responsibility." She uses multiple alarms. Tracking apps. Daily routines. And, like so many others, she deeply values connection. "The Zoom groups are so important. They are my connections."

I asked Margaret what she thought helped her live her best life on a day-to-day basis, "I'm going to say it's the way I think about and approach each day. That, and Parkinson's Association of Alberta," she shared. "And I mean it because the first thing my neurologist told me to do was call Parkinson's Association of Alberta and become a member, which I did. And then I went back to dealing with the cancer." She explained that the connection to PAA provided pivotal education, support, and community during an incredibly difficult chapter of her life. Margaret also spoke beautifully about finding joy.

"I tend to appreciate things more. Just the little things like being able to watch the clouds or listen to my favorite music. I actually did a silly thing the other day, I went through and figured out what was the number one song at the time of my birthday for every year I've been alive." And of course - she made a playlist.

Perhaps one of the most illuminating insights came when I asked whether she had any fears about the future. "I'm not scared or afraid," she said. "I'm curious and cautious." An honest, vulnerable, and wonderfully human answer. But there was one more gem. Margaret gracefully replied when asked if she had any goals or plans, she wanted to achieve knowing her diagnosis? "No, I think just to enjoy each day as it comes." In her words: "It's the ability to still enjoy doing them." Of course - while wearing a perfectly appropriate t-shirt to start a conversation and bring a smile.

Dwayne & Shelley L. have been on the Parkinson's journey for twenty years and help highlight how a diagnosis affects (albeit in different ways) both the person diagnosed and their families. Because Dwayne was only 45 when symptoms first appeared, they were initially told it was not Parkinson's. "And so, we left there thinking, oh, thank goodness it's not Parkinson's because that was our fear. And we kind of just put it out of our heads," Shelley stated. "And then two years later, I started having friends say to me, you know, something's not right with Dwayne. Our kids would come home, and they would say they knew there was something wrong with their dad. So, I promised them we'd go see the doctor again."

When Dwayne was diagnosed at the age of 48, "We were already very familiar with it," Shelley explained. Dwayne's father had also lived with Parkinson's, and they had already seen what the disease could do. "Dwayne took it really tough because he was in denial."

Today, more than twenty years later, Dwayne continues to remain active, engaged, and involved in his community. When I met them, what stood out was their partnership. When I asked what they would tell their younger selves, Shelley offered a unique perspective. "To be honest, I'm going to say it was a blessing." Then she paused. "I'm going to really explain that because a blessing is a pretty broad word. The reason I say that is that you spend your whole life working towards retirement. And we planned that. And when Dwayne got this diagnosis at 48 years old, we knew retirement was now going to look different. And so, we started traveling right away. We honestly have tried to live more for today than we would have otherwise."

I asked both: "So what could you say you're grateful for?" "The progression hasn't been as bad as I thought it was going to be," Dwayne shared. Shelley added, "And I would say we're grateful for family and friends." Their son has spent ten years organizing a Parkinson fundraiser that has raised over half a million dollars. Their children and grandchildren stay central to their lives and why they also live part time in Calgary. "They've been extremely supportive and continue to be."

And what advice would they would offer someone newly diagnosed, Dwayne answered quickly.

"Get active and stay active." Shelley added her own perspective. "It's not an easy journey. Acceptance is the biggest thing. Don't beat yourself up." She spoke about grieving each stage as Parkinson's changes. "Nobody can really understand this disease until you're walking a mile in those shoes." Yet despite the challenges, they continue walking this

journey together, between two provinces - half the time in Saskatoon & the other in Calgary.

If you spend more than five minutes talking with Dulcie W., two things become clear. 1) She tells it like it is, and 2) she will almost certainly make you laugh while doing it. Living in a rural community, Dulcie's Parkinson's journey looks different than urban and suburban dwelling peers. Accessing specialized care means early mornings, long drives, planning around weather, and a different level of preparation that many in the city rarely need to consider. Yet despite those challenges, she approaches life with equal parts of realism and humour.

When I asked if she felt she had lost anything since being diagnosed with Parkinson's, she paused before answering. "I had a better sense of self, of wholeness." An honest and powerful reflection that she acknowledged before shifting toward what she has learned rather than what she has lost. One of those learning moments came through her new DBS journey. Dulcie explained how she expected DBS to work like a “light switch.” Instead, she has learned what so many others eventually discover: All remarkable things take time, healing takes time, programming takes time, and patience is often one of the hardest skills to practice when we are a society that wants instant results.

When I asked her what she wished she had known in those early days after diagnosis, her answer wasn't about medications or exercise; it was about living. She shared (she wished she understood) "How much my life is going to change.” “I think I would have done more in the time that I was, you know, the honeymoon period, when you're doing really well, I would have done more, I think.” Then added: "More travel, more physical stuff while I have the parts that were working. But the other thing I would say to myself is that no, your life isn't over.” Not said with the least bit of regret but rather because Parkinson's has taught her that time is precious. That the things we keep saving for later deserve our attention today.

As our conversation ended, I asked what she would tell someone newly diagnosed. Her answer was simple and beautiful and perhaps my favourite piece of the entire interview: "Your life isn't over." Then she added another piece of her golden wisdom that seems to summarize her entire approach to living with Parkinson's: "You do learn to appreciate what's important to you." Perhaps that is what Dulcie's story is about -- appreciating what matters, laughing whenever possible, and refusing to let Parkinson’s have the final word.

I want to thank everyone who took the time to share their stories, insights and experiences with me. An amazing group of people who (like the Parkinson’s Community as a whole) continue to choose life, purpose, humour, connection, and hope, even when the road ahead is uncertain. None of their journeys look alike, yet every one of them shared something remarkably similar. The story of resilience. ■

