

COLUMN: What it's like to live with Parkinson's Disease



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April is Parkinson's Awareness month. I would like share my story with you to hopefully help bring a better understanding of what it's like to have Parkinson's Disease.

An estimated 11,000 individuals live with Parkinson's in BC and over 100,000 in Canada. Parkinson's is the second most common chronic neurodegenerative disorder. It is caused by a loss of dopamine in the brain. There is no cure but there are treatments such as medication, surgery, and physical, occupational, speech therapies that can assist in coping with this disorder. There is wealth of more information and support if you contact the Parkinson Society BC at 1-800-668-3330.

Now on to my life with Parkinson's. In April or May of 2013 I noticed a couple of things with my left hand/arm which didn't seem normal. It didn't swing normally when I walked. Also I found it took me a long time to get stuff (such as ball markers for golf) out of my left pocket. In June I decided to go to my family doctor in Salmo, who suspected I may have Parkinson's.

I had tests done to rule out other possible causes of my symptoms. I started doing my own research. I went to a neurologist (to get an appointment can take six months or more and to see a movement disorder specialist can take up to a year in BC) in September 2013 and my family doctor's diagnosis was confirmed. I have Parkinson's.

It was shock and a relief at the same time. Now I know what is happening and can move on. I got in touch with

the Parkinson's Society of BC right away and they were very helpful. Then I joined the Trail/Castlegar Parkinson's support group. Our group is individuals with Parkinson's and their caregivers. We meet monthly except July and August on the third Tuesday from 11:30 to 2 p.m. in Trail at the Colander restaurant.

I started attending the Parkinson's exercise group, facilitated by physiotherapist Joanne Robbins. We are very lucky to have a physiotherapist at Kootenay Boundary Regional Hospital who specializes in working with individuals with Parkinson's. The exercise group was started in 2014. This past year I have not attended as many sessions because it hard getting away from work.

Exercise is very important for people with Parkinson's because we need to keep our muscles moving. Parkinson's affects part of the brain that makes your muscles work properly. Exercise is also good because it retrains our brain to make new pathways which helps keep us moving. I was doing great exercising when I was first diagnosed, playing hockey, walking, and yoga.

Then around May/June 2014, my medication was causing a negative side effect. I will not get into details, but I had to change my medication. I went through a rough time for eight months or so. I wasn't exercising as much as I needed to. I was dealing with depression and apathy — which can both be part of having Parkinson's. The hard part is these non-motor symptoms which people can't see can be worse than the physical symptoms (tremors, slowness, talking softly).

A weird part of my eight month period when I wasn't doing well is that Robin Williams committed suicide and it was reported he just learned he had Parkinson's. Kind of scary. That's why it's good to have a strong support network.

I need to note I told my employer I had Parkinson's as soon as I was diagnosed. My employer has been very accommodating with my needs. I ended up taking four months off work (December 2014 to April 2015) and used this time to readjust my medication after going to a movement disorder specialist at the Pacific Parkinson's Centre at UBC.

I got help with my depression which has helped me considerably. I started exercising again and this still a work in progress. I am noticing more motor symptoms now. For example, I am walking slower, have more tremors, my fine motor skills are not good and my balance is not as good. I am still not 100 per cent comfortable with my symptoms around co-workers and the public but I know I will have to deal with it because this is who I am now.

There is now a doctor in Kelowna that specializes in movement disorders. Dr. Daryl Wile has opened the Okanagan Movement Disorder clinic at the Kelowna hospital in partnership with the IHA, UBC faculty of medicine, Parkinson's Society of BC and support groups. This is great for people with Parkinson's because they don't have to drive so far to see a specialist.

Another note: I have attended three one-day Parkinson's Society of BC conferences/workshops since I was diagnosed. I really feel educating myself and connecting with other positive Parkinson's people keeps me moving forward with living with the disease. Educating as many people as possible is another positive that keeps me feeling good.

Something important I have to mention is how supportive my family and friends have been with everything I do around Parkinson's Disease awareness efforts. It is neat how I will get phone calls and/or people stopping me on the street to tell me about something they read or saw on the news about new Parkinson's Disease treatments or new exercise that will help me.

I am planning to attend the World Parkinson Congress in Portland this September. It is very exciting to have this so close to us.

I am doing a fundraiser this year for the Parkinson's Society of BC. My goal is to walk 550,000 steps from Feb. 14 to April 10, which is 10,000 steps per day. I am hoping to raise \$1,000. There is a link on the Parkinson's Society of BC website to donate.

For more information or questions about the fundraiser or Parkinson's you can call me at 250-608-2865.

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