What are the symptoms of LBD?

- **Visual hallucinations**
- **Movement disorders**
- **Poor regulation of body functions (autonomic nervous system)**
- **Cognitive problems**
- **Sleep difficulties**
- **Fluctuating attention**
- **Depression**
- **Apathy**

LBD Resources

The Lewy Body Society
https://www.lewybody.org
The Lewy Body Resource Center
https://lewybodyresourcecenter.org/
Lewy Body Association
https://www.lbda.org/
Lewy Body Dementia
http://www.lewybodydementia.ca/
Alzheimers Society Canada
https://www.facebook.com/AlzheimerCanada/
Lewy Body Dementia Canada
https://www.facebook.com/Lewy.ca/
Lewy Body Association
https://www.facebook.com/LewyBodyDementia/
Lewy Body Resource Center
https://www.facebook.com/lewybodyNY/
The Mayo Clinic
https://www.mayoclinic.org/
Dementia Support
http://www.dementiasupport.ca/

What is Lewy Body Dementia?

Lewy Body Dementia (LBD) is a form of dementia that occurs because of abnormal deposits of a protein called alpha-synuclein inside the brain's nerve cells. These deposits are called "Lewy bodies," after the scientist who first described them. The deposits interrupt the brain's messages and affect the areas of the brain that involve thinking and movement. We do not yet know why or how these Lewy Bodies form. LBD can occur by itself, or together with Alzheimer's disease or Parkinson's and it accounts for 5-15% of all dementias.

Unfortunately, there is not a lot known about the genetics of Lewy Body Dementia. This is due to the fact that there hasn't been much research done into that area of the disease yet. With that being said, there are some newer studies that suggest up to 60% of the risk of getting the disease is genetically predetermined.

As of right now, there is no cure. LBD is fatal.

CANADIAN LBD INFORMATION

OPENNESS, COMPASSION & CLARITY

canadianlbdinfo.ca

CANADIAN LEWY BODY DEMENTIA INFORMATION.

https://www.facebook.com/CanadianLBDInfo

Our Story

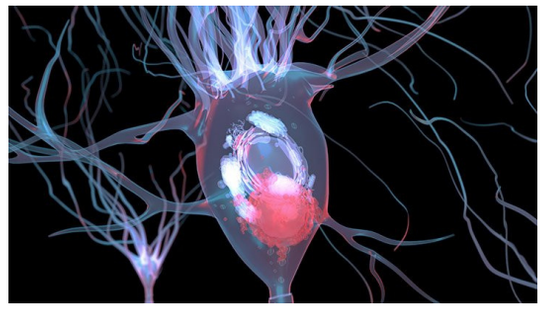
My name is H. Carol Schmidt. I was my beloved husband Bob Schmidt's fiercest advocate and care partner. Bob was cared for at Sunnyside Residence at Laurel Creek unit in Kitchener, Ontario. I would like to share our story and hopefully give you enough information about Lewy Body Dementia so that in the future you are able to ask the right questions to your medical team.

Our journey began long before we knew Bob had LBD. Lewy hides, operating much like an a stealth helicopter, and can hit you when you least expect it. Often you simply do not know what is happening when the attacks come. It can be very confusing if you do not know what is happening or what to look for.

In the early 90's Bob was vice-principal at Waterloo Oxford high school. During that time, there was a Secondary Teachers' Strike. Suffice to say, it was a tense time at work for him. Bob was always the epitome of calm, no matter what crisis he faced. However, at night, the stress manifested itself with REM difficulties (known as REM Sleep Behavioural Disorder) where he was physical acting out his dreams and flailing his arms and legs in bed. We assumed it was stress related and moved on.

A decade later, due to family stress brought on by caring for our aging and ill parents, the REM difficulties began again. They were off and on and less obvious this time around. So, again, we laughed it off and forgot about it.

In February 2015, Bob had a stroke which affected his language center. After the stroke Bob developed aphasia. He was also hit in his cerebellum and developed balance issues. After he was discharged from the hospital, it took us about 9 months to find a therapist for the problems caused by said stroke. We carried on but the REM difficulties were becoming more prevalent, as was the saliva difficulty, which were never fully diagnosed.

Finally Bob's family doctor sent us to a young neurologist who had just begun his practice. We met with the neurologist in Sept. 2017. He spent 2 hours with us and then diagnosed Bob tentatively with Parkinsonian-like symptoms. Our second visit with the neurologist happened about a month or so later and lasted a good hour. That was when we were given the LBD diagnosis. I call that D-Day. Devastation Day. We were absolutely stunned. At that moment, I was struck dumb.

On February 8, 2020, Bob lost his battle with LBD but gave us one last gift; he donated his brain to the LBD research at the Robarts Research Institute at the University of Western Ontario. I continue to advocate for those who have been diagnosed with LBD and their families to honour Bob's memory. Bob was a Lewy Warrior and so am I. My mission is to advocate, educate and raise funds for LBD research.