

# ALS easier with the support of family and friends

Most nights I dream that I can walk or run or at least stand. But instead of waking up from a nightmare with a sense of relief, I wake up to a nightmare where even getting off my bed is a struggle.

I was diagnosed with limb-onset ALS in August 2017. Limb-onset means the problems started in one's legs or arms. A person diagnosed with bulbar-onset first experiences symptoms in their mouth, larynx or throat.

Nothing shakes a life to its core than a diagnosis of a disease like ALS. Although we all know we will be checking out one day, we can't imagine it will happen any time sooner than the very distant future. And, of course, like any seismic shift, it profoundly affects your loved ones, family, friends and relatives.

But seismic shifts can bring tremendous benefits too. In my case, it was the reshaping of our family dynamic. We are a loud group, with lots of joy and frustration being expressed at all times of the day or night. And lots of friction and standing your ground. Suddenly, everyone was kinder to each other and cognizant that this precious thing we have will not remain intact forever. We all say "I love you" more than we ever did, and little transgressions are more likely to be overlooked.

My sister, Vicki, was desperate to do anything to help me and to show her love. So when the BMO Marathon for ALS BC was announced, she immediately signed up and started to train. My daughter, Hannah, also quickly joined up and started collecting sponsors. Her pledged totals started to climb and quickly outpaced Vicki's.

For a while, Hannah's pledges topped all ALS donations for the run.

On the day of the run, we decided it would too difficult for me to cheer them on at the finish line. At the time I did not have a powered wheelchair and was using a walker. The



The Stehr-So Family

ALS Society had lent me a walker/wheelchair (among other items) but having to face the long distance from a parking spot through crowded streets and sidewalks to the finish line was too much to bear. So I installed a tracking app and followed Vicki and Hannah as they ran the half-marathon. They were also joined by my nephew, Sam. Always amazing, Sam ran the full marathon. He had bicycled across Canada a few years earlier, so I should not have been surprised that he was able to complete the run. Hannah, Vicki and Sam completed the run and together raised about \$4 000 for the ALS Society of BC.

The slow and relentless decline from ALS is hard to deal with, and it is almost impossible to stay in the

moment and appreciate what you have now. But unlike a sudden ending such as, for example, a fatal heart attack, the slow decline offers the time for me to tell and show those around me how much I love them and value their friendship and caring. And it gives me the opportunity to break free from the negativity we often find in our family dynamics.

And importantly, the extra time allows those close to me to show their love, whether by running in a marathon, building something for me that aids accessibility, or coming over to weed our garden. The nightmare seems easier to wake up to when family, friends and relatives gather and support me. Most importantly, they let me know that my life has mattered to them.

## What is ALS or Lou Gehrig's Disease?

Amyotrophic Lateral Sclerosis (ALS) is a rapidly progressive, neuromuscular disease. It attacks the motor neurons that transmit electrical impulses from the brain to the voluntary muscles in the body. When they fail to receive messages, the muscles lose strength, atrophy and die.

ALS can strike anyone at anytime, regardless of age, gender, or ethnic origin. It does not affect the senses, and only rarely does it affect the mind. The equipment costs for each patient average \$140,000, while nursing and home care costs can be up to 10 times this amount.

The ALS Society of B.C. is dedicated to providing direct support to ALS patients, their families and caregivers, to ensure the best quality of life possible living with ALS. Through assisting research, we are committed to find the cause of, and cure for ALS.

## Victoria WALK for ALS



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Registration: 11:30 am | Walk Starts: 1:00 pm

FOR MORE INFORMATION  
Walk Coordinator - Sean Houlihan  
[victoriawalk@alsbc.ca](mailto:victoriawalk@alsbc.ca)

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**WWW.ALSBC.CA WE NEED YOUR HELP.**

To learn more about ALS or to make a donation online visit [www.alsbc.ca](http://www.alsbc.ca)

Phone: 604.278.2257 | Email: [info@alsbc.ca](mailto:info@alsbc.ca)

ALS Society of BC: 1233-13351 Commerce Parkway, Richmond B.C. V6V 2X7



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