

BULLETIN

## ALS: when a physiotherapist is diagnosed

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by YUKIE KURAHASHI



**hen she answers the door** to her suburban Victoria home, her facelights up. She seems just as shes always been: lively, with that mischievous light in her eyes. But former HSA board member Jenny Robertson is facing new challenges.

An occupational therapist is just heading out the door, saying her goodbyes and rattling off last-minute instructions; Robertson nods and smiles. Then, in response to a question, she carefully articulates what sounds at first like a series of open vowel sounds. She is starting to lose control over the muscles in her tongue and throat.

Robertson has been diagnosed with ALS ... or amyotrophic lateral sclerosis, also called Lou Gehrig's Disease. ALS is a progressive neurodegenerative disease. As a physiotherapist at GF Strong in Vancouver, Robertson saw, assessed, and helped treat many clients with the disease. She never dreamed she'd one day become a client.

-It started with weakness in my knee, after an injury," she says, sometimes speaking with the aid of her brand new keyboard communication device.

-This is new, I'm still getting used to it," she adds as an aside, before continuing.

-Anyway, five months later, it was my thumb. I lost feeling in it. And then my tongue. My *tongue*," she points.

Anguish clouds her face for a moment. She stops typing, and slowly enunciates: -I knew. Because I'm a physio, I knew what it was. Because of the motor weakness and tongue involvement, I was afraid it was ALS."

Robertson was made to wait three months to see a specialist. -That was February 2007," she says. -By that time I was already off work. December. December 2006. I had to stop working."

For the first time ... as she talks about her work ... Robertson betrays her grief. -I loved my job," she says, and her eyes fill with tears. -*I loved my job*. I loved it."

And so she kept working. Even though she could no longer see clients, Robertson continued preparing her presentation for the World Confederation for Physical Therapy, to take place that summer. -I still went to the conference," she says. -I was surprised by the distances I had to walk at Canada Place, and that was tough, but I'm so glad I went. It was great to see people learning from the research we put into our poster."

In addition, Robertson was originally scheduled to teach a post-conference course. -But I mostly observed and helped with paperwork. This was hard ... I knew it was the end of my career, maybe the last thing I would do ... but I still have one research paper," she smiles. -I just have to read it over and approve it, and have it published," she says.

Since her diagnosis, she has had to make many changes. Just months ago, she sold her apartment in Vancouver. For the first time, Robertson now lives with her partner. -Its so nice to live together, finally," she laughs.

Jenny Robertson Physiotherapist GF Strong Rehabilitation Centre
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Robertson is a former chief steward at GF Strong in Vancouver, as well as a former Region 4 representative on HSAs Board of Directors. But through all her years of activism, few colleagues suspected a long distance love affair.

-We met seven years ago," she says, blushing. Where? -At our 30th high school reunion," she says. And smiles, withholding the punchline.

-He was my boyfriend in high school."

Why did they not live together before?

-Because I loved my work," she says. -*I loved my work*. I loved it. I loved being a physio."

Her partner, Gary, now looks after many of the household chores and helps ensure Robertson has all the supports she needs. -Hes been so wonderful," she says.

Her expertise as a physio is constantly in use ... this time, for Gary, and for herself. -It helps me advocate for myself," she says. -And I can also educate Gary, because often he doesnt understand the needs or the equipment.

-Increasingly, I need to use the equipment not because I absolutely need it but because I want to save my energy," she says.

The occupational therapist visiting that day had been fitting Robertson for her first motorized wheelchair. After helping her set it up, they tested it on the steep incline of the driveway.

Its obvious she relishes talking about the complexities of this process. -She helped me choose the appropriate wheelchair. To do that, she takes various measurements including my leg length and back width. Then we need to determine the future needs for the chair, and consider tilt and recline," she explains.

-Then theres something called a Roho cushion. Whats a Roho cushion? It redistributes weight evenly to prevent pressure sores, and they also have to adjust the level of inflation to the individual.

-I go to the ALS team at GF Strong," she says. -The people who see me there were my coworkers just a few months ago. Its really hard. But Im so grateful."

Recently, after being assessed by a speech / language pathologist, Robertson was supplied with the keyboard communicator. Because she is starting to have difficulty swallowing, she was advised to make alterations in her diet.

-Im now modifying my food so its easier to swallow," she said. -The speech / language pathologist also referred me to a dietitian. Together, they advised that I add smoothies to my diet to increase my weight. Im also grinding up salads and soups, and Ive been advised to eat slowly and take smaller bites," she says.

-Sometimes Ive been frustrated because I was so fiercely independent before," she says. -So, getting used to asking for help really hurt. Thats still hard for me."

Robertson explains that for a patient like her with ALS, doctors play only a minor role. -Its health science professionals who are the most necessary part of the ALS team," she says. -Im so grateful for all the help and assessments Ive had from my colleagues. They are really, really, dedicated."

â€ˆD sounds are becoming tougher for her to pronounce. She repeats herself.

-Dedicated. And caring. I know its tough for them, too." 

*Jenny Robertson is a physiotherapist, and has represented Region 4 on HSAs board of directors. She has also been a member at large for Region 4, as well as chief steward for GF Strong Rehabilitation Centre in Vancouver.*

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