



“You have ALS.”

Those three little letters pack such a huge punch.

It wasn't supposed to be this way.

I met Margaret, the love of my life, in 2002, and we were married in 2004. We traveled a lot (Australia, New Zealand, Egypt, Costa Rica, Britain, Ireland, Africa), and at the same time enjoyed our sweet little bungalow in Steveston. We were having loads of fun, and our lives were happily mapped out in front of us.

Little did we know how drastically those dreams, plans and lives would change.

I was born and raised in Montreal. In the summer of 1981, at the age of 29, I moved to Vancouver where, very shortly afterward, I got a job with Canada Post.

In April 2011, after 30 years as a letter carrier, I retired — and started making plans for the rest of my life. A week later, I noticed a funny little problem with my right index finger: I couldn't make the letter “R” in sign language. I was also getting occasional painless spasms in my other fingers.

At first, it was thought that I might have tendonitis and an electrolyte imbalance. Months later, the second plastic surgeon I saw discerned a very small loss of muscle in my hand and referred me to a neurologist. After the testing and an MRI, I was told that I had ALS.

It was Nov. 23, 2011.

I was devastated, as was Margaret. Then we faced the difficult task of sharing this shattering news with family and friends. Since my family are all in Ontario and Quebec, it has been particularly difficult for all of us to have this distance between.

Still, the love, support and offers of help we have both received have been incredible. There are so many people we can call on, if we need any assistance. As my condition worsens, we will be making many more of those calls.

Margaret is a member of Abreast In A Boat, a breast cancer survivor dragon boat team here, and I have been the manager of her crew for the last eight years. She and the other fabulous women in this group have led the way in showing me how to live for today. It has been, and continues to be, a great lesson.

It's been a year now since I heard the words, “You have ALS” — those three little letters that pack such a huge punch. I've learned a lot: for instance, that 80 per cent of people with this disease will die within five years; that, every day, two or three Canadians will succumb; that equipment costs for patients average \$137,000, while nursing and home care costs can be up to 10 times that amount; that there is no significant treatment and no cure — yet.

I've also learned that researchers in Canada and around the world have made huge strides toward understanding this disease and possibly finding a cure. That has made me more determined than ever before to get the word out. The more we can raise awareness — and money — the sooner we can celebrate that discovery.

With the year that has passed, so too has my shock. We are both getting on with life. I am more consciously living in the moment, and enjoying it.

Writing a blog, www.shее-myals.blogspot.com, has helped me share my experience with those who care.

After I was diagnosed, my doctor wrote this to me: “I will share my philosophy about life in general... Being in this business, I can say that none of us knows what is around the corner and, if you are able, it is best to do what you want, when you want, rather than putting things off. I think this goes for everyone, and not just people with ALS. Unfortunately, it often takes a bad disease, however, for people to get the ‘push’ to do this.”

And so I find that I am counting my blessings more than I ever did before. I am fortunate in that the progression of my disease seems to be slower than average. Yes, I have lost most of the muscles in my hands, and some in my arms and legs. Everything I lift feels much heavier than before, and I don't walk as fast or as long as I used to. But adaptation has become my middle name, and I ask for help when I need it. And this whole journey is made easier by the great team of professionals at the ALS Centre at G.F. Strong, as well as the amazing women at ALS BC.

My spirit is good. I have decided that it's not going to get me until it gets me.

SHEILA TYNAN



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