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Photo: Trevor Millions, TMJ Photography

Robert Boulton with his full-time caregiver Arinaldo Maon. Aging with a serious, chronic illness has helped Boulton to find peace and overcome his fear of death.

Robert Boulton

ALS steals your body, not your soul

I never thought much about my mortality. I had a beautiful wife, a great home and job, and was surrounded by caring family and friends.

My life changed in 2010 when I was diagnosed with ALS, amyotrophic lateral sclerosis, also known as Lou Gehrig's disease. It is a progressive neurodegenerative illness. There is no cure.

Faced with no hope for the future at age 42, I had to look deep inside to conquer my greatest fear, death.

Once I made peace with dying, I was free to live a limitless life. There is a clarity that comes naturally when you are forced from society and to watch from the perimeter. No clouds linger, no thoughts are incomplete. I no longer

go to bed worrying about staff and a heavy to-do list continually scrolling through my brain.


I do wish I could still talk (I use technology to communicate by blinking), but as a dying man, quiet reflection allows time to prepare my heart and soul for any and all challenges. I am free to dream and imagine a better world for all who suffer, and create projects to make it happen.

After I was accepted into Alberta Health Services' self-managed care program, part of AHS's home care program, I found a live-in nurse, Arnie Maon.

Not only have we laughed a lot, we have schemed about how to use my exceptional computer skills and ideas.

We sell T-shirts internationally with my new motto: ALS Steals Your Body—Not Your Soul. We partnered with a southern Alberta company, CattleBoyZ, on its launch of a new barbecue sauce, Chipotle, Maple and Bacon, to put my image and a message about ALS on the label to support research and raise awareness.

Now, I am focused on my legacy of caring for Alberta and the world, in a project that everyone can be part of, TheBoultonProject.Com. The project's goal is to help Alberta charities meet their donation targets and complete special projects.

I want to leave a permanent mark of hope. 

— As told to Jacqueline Louie