

Duxbury Reporter

The Drive of a Lifetime

July 13, 2007

If you told someone you planned on spending part of your summer vacation in a minivan driving through the Sonoran desert with your mother-in-law, they'd probably offer either sympathy or the number for a good psychoanalyst.

Last August, that's exactly what I did. My wife, two young sons, mother-in-law and brother-in-law got into a car in Tucson, Ariz. And drove the approximately 470 miles to the Orange County coast of California.

Why do it? It wasn't for the weather, since they consider anything below 100 degrees a cold snap in Arizona. In fact, in the past, my in-laws usually came to visit us. But this wasn't a normal time.

In July of 2005, my mother-in-law's speech started to slur. It took many doctors, both here and out west to determine the cause. Finally, a doctor came up with a diagnosis, bulbar ALS, essentially amyotrophic lateral sclerosis that begins in the jaw.

Between the summer of 2005 and the summer of 2006, ALS robbed Cecilia Barcelo, my mother-in-law, of the ability to speak. Thankfully, good handwriting and a talking computer allowed Ceil, as we called her, to communicate with the world. By the time we saw her that August, the disease had started to work on her lower body, requiring her to use a walker regularly.

So, we took a long drive through the desert because we knew it was really our last chance. Truth be told, at the time it could be a trying experience. The drive was long and our stops, for food or relief, were complicated affairs involving unfolding Ceil's walker, keeping track of two boys with energy no minivan can contain and did I mention my brother-in-law, John, is blind?

But we made it to California, where we saw relatives we rarely get to see, visited a famous mouse and ate burgers on a Balboa pier. While Ceil declined to visit the mouse, she did go for the burgers. And she walked the length of the pier, slowly. But she made it from one end to the other.

The next time I saw her was February of this year. We moved her and John east to be with us, since despite her heroic efforts, she could no longer care for the both of them. In seven months since I had seen her last, she had noticeably declined. She could only use her walker for short distances and the ALS not only made talking impossible, but eating was becoming a trial too.

It's probably unfair to label one fatal disease worse than another, but ALS is a rotten disease, one that slowly strips a person of control of their body, until all they have left are the thoughts in their head. But one comfort for those facing it is the network of support available. The Massachusetts Chapter of the ALS Association provided equipment, and the nurses and volunteers of the Cape Cod Hospice handled a variety of tasks, some very difficult.

Two people deserve special recognition. First is Ron Hoffman, founder of Compassionate Care ALS, a non-profit group based in Falmouth, dedicated to providing services to those suffering from the disease and their families. Ron was always helpful, providing equipment and advice in a gentle, understanding way.

The other person who deserves recognition, and far more than I can give here, is Ceil's daughter, and my wife, Ann. Faced with losing her mother only two years after her father died, she cared for Ceil with dignity, hard work and yes, some tears. It wasn't easy and I can't honestly say I could do what she did.

Cecilia Rosaria Barcelo died July 3 at the Cape Cod Hospice with her daughter at her side.

So yes, maybe you wouldn't normally get into a car and drive through the desert with your mother-in-law. But the truth is, you only have some many chances to be with the ones you love and you have to take advantage of them. Even if it requires a minivan.

In honor of Cecilia Barcelo, Team Ceil has been created to sponsor a runner in this year's Falmouth Road Race on Aug. 1 and to raise funds for Compassionate Care ALS. Go to www.ccals.org and click on the Falmouth Road Race box for help.