

*Bruce Richardson's wife, Diana, was diagnosed with Pick's Disease in 1999, when they had been married for 33 years. He cared for her at their home until her death last year. Here, Bruce generously shares his thoughts and feelings about her illness, her death, and the ambivalence he feels now that he has been "freed" from his role as a caregiver.*

Diana died in her sleep on April 7, 2006. Her death was not a surprise; I had been expecting it for many years and it brought mixed emotions. On one hand it was very sad, but on the other it was a relief – her suffering was over and my role as a caregiver was complete.

I had been a full-time caregiver for four and a half years. The first year of caregiving was the hardest. I would get mad at Diana for doing dumb, illogical things. She was "emotionally flatlined" and I couldn't carry on a conversation with her. I think it took about a year before I began to accept the fact that Diana really had no control over her emotions or actions. Once I fully understood that, I could deal with her much better.

One of the harder things was not being able to communicate with Diana. She was mute the last year of her life, and for the last three to four years she could only speak a few words at a time. I was able to tell her things but she couldn't respond. I was never sure she understood what I was saying – but I knew what I was saying, and it helped me to be able to tell her I loved her and tell her about our kids and our new grandchild.



Caregiving is a mixed bag. It is sad watching your spouse slowly fade away, but the work of daily living can crowd out the larger, emotional issues. Most married couples have fallen into a routine, where each does certain chores around the house. Then all of a sudden, when FTD hits, one spouse is left to do everything. At the support group I belong to in Denver I have heard stories of spouses who have never cooked, never taken the car in for maintenance, never paid bills, and people who had never heard of a durable power of attorney. I was fortunate in that I am quite handy around the house, I love to cook, and I was able to deal with most everything, although I really dislike cleaning house--as anyone who has visited me can attest to.

One of the heaviest burdens of caregiving is the loneliness. Some people have a fear of being with someone with dementia – they don't know what to do or what to say. I was probably one of those people prior to Diana's illness. After her symptoms became evident we had fewer visitors and we were not invited out nearly as much as we had been previously. I have had a few people be honest with me and they said they just felt awkward being around Diana, so they stopped calling – I understand that and I am OK with it.

Another burden is having mixed emotions: the sadness of losing your spouse and the guilt feelings from being relieved of your caregiving. In my experience a caregiver comes face-to-face with this guilt at two junctures: when they consider putting their loved one into a care facility, and when he or she finally dies. I must say, when Diana died I did feel relief, along with the sadness.

Everyone has their own view of death and of how they would like it to happen for themselves and for those they love. Some people want to squeeze every minute out of their life regardless of their condition and quality of life, and others are just willing to let nature take its course and get it over with. I take the latter view point. Two books I found very helpful were *Dying Well* by Dr. Ira Byock, and *Final Gifts* by Maggie Callanan & Patricia Kelley.

For me it was an honor and a privilege to care for Diana. There is very little I would have done differently. Other than her illness and death, the only regret I have is that I didn't recognize her unusual behavior as an illness earlier than I did. I do believe that I am a better person because of the years I spent taking care of Diana. I miss her, but I am trying to move on with my life and be a good father and grandfather for my kids.