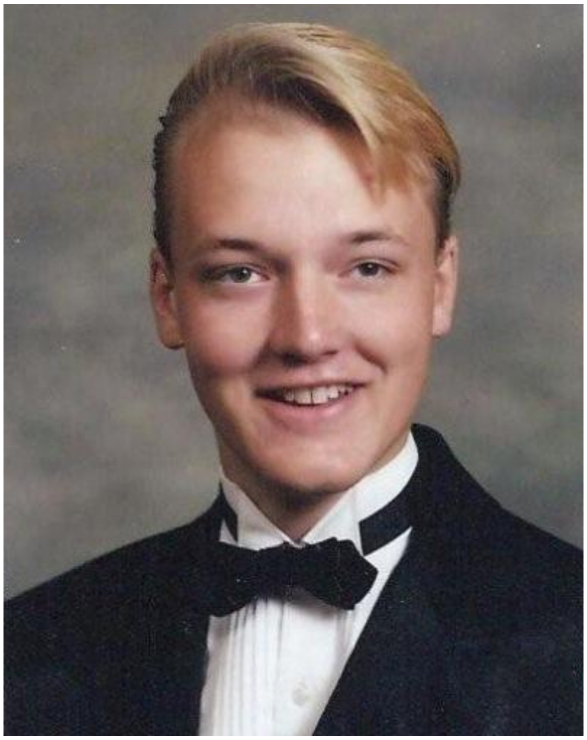
Jeanine's son Bryan died on June 12. He was just 31, with a young wife and infant daughter, when he was diagnosed with FTD two years before. Here, Jeanine writes of the unique heartache a mother feels watching her child succumb to this disorder, and of her search to find some meaning and a way to cope.



When my son was diagnosed with Pick's Disease at thirty-one years old, it was without a doubt the worst day of my life. First came disbelief, then anger and confusion. I was devastated.

Bryan was also my friend. He was a man of character and strength. He was mature and made good decisions; he could make me laugh hysterically and he was the person I called when I needed a lift. We had an easy relationship that required little, but brought me so much happiness. When I looked at my son, I felt that I had done something right.

I watched helplessly as Bryan changed. He became emotionally flat and his personality altered so much it was hard to remember the person he once was. My sadness and frustration were overpowering as I watched him slip away an inch at a time.

For almost three years I traveled back and forth from Orlando to Salt Lake City to help with his care. My visits consisted of running errands, doing household chores, spending time with my granddaughter and giving my daughter-in-law a much-needed break. My entire focus was on my son, his family, and how I could help. The trips were emotionally and physically exhausting.

Before long, this disease began to take a toll on me, too. I was so exhausted there was nothing left in me, for me. I no longer exercised or cared what I ate. How I looked didn't matter. Sometimes I left the house in my pajamas and slippers to take Bryan for a Slurpee at 7-11; something I never would have dreamed I would do, but at the time it seemed "normal." There were nights that I would drop into bed without ever taking a shower or combing my hair for the entire day.

My extended family and employer were all very supportive. But it was difficult for me to admit that, for the first time in my life, I couldn't do it all. I was thankful for their help and at the same time felt uncomfortable accepting such generosity. My life was becoming an open book, and I felt completely "exposed". This was especially difficult because I have always been an extremely private person.

When I was in Salt Lake with my son and his family I found the strength that I needed. But when I left, I would cry the entire way home to Orlando. At night I couldn't sleep, so I began to write a journal about everything that was happening. It gave me the release I needed. I wrote and I cried, and I wrote some more and then I cried. Writing is a good outlet for people like me who want to keep things private. Seeing my sorrow on paper somehow gave me comfort, so I continued to write: More than 300 pages describing my son's life, his behaviors and the progression of the disease.

Bryan is gone now, and I am relieved that he is no longer suffering; seeing his frustration and deterioration gave me the courage to let him go.

I know my son would want me to go on living, and I really am trying. I want his life and what he went through to mean something; so I search for a purpose. Getting up each morning is still a chore, but I'm getting up. Long term I don't have a clue what to do. My immediate goal is to write a book of happy memories about Bryan. I want to give this gift to my granddaughter who is only four years old. I want to share with her the happy stories about her daddy; to help her to know him, even though she may never remember him. I want her to know her daddy was someone very special; that he and her mommy shared a great love for her and for each other. My purpose has become keeping Bryan's memory alive.