

## **Something about Mary. Written by Cheryl Fischer**

*Cheryl describes her mother, Mary, as vibrant, full of life and an inspiration for how to enjoy life. In this essay however, she presents some of the challenges their family has faced providing care for Mary as she battled FTD these past 13 years. Caregivers honor their loved ones daily with both small and heroic demonstrations of love in the long journey that is FTD.*

Mary was the most vibrant, full of life person I've known. She was a true inspiration for how to enjoy life, and she was my Mom. Unfortunately, Mary was stricken with FTD (Pick's Disease) at an early age, probably somewhere around 60 or 62. I could talk about mom and how this has changed our lives, but I wanted to share a different story which focuses on the disease and the care.

Initially, the changes were very subtle and we didn't really notice them; I guess that comes from being so close. But as time went on, it was evident that she couldn't do things which in her past were done without even thinking, like making our favorite Italian dinner. It seemed to be memory related and she didn't seem old enough to have age related issues. But then she began showing symptoms that were alarming to us and cause for a visit to the doctor.

Her gait was off when she walked and she would lean towards one side or seem crooked. She became obsessive when she ate not wanting to stop. She couldn't remember how to do things like cook, balance a checkbook, drive, or find her way to the bathroom. She had an increase in sexual activities. She had forgotten how to take care of herself and became distant. She really didn't engage in conversations and stopped calling me, forgetting birthdays. She would walk around lost in her own home.

Not sure of what to think, we began down the medical path. The general physician had no clue and immediately labeled this "age related". Then we encountered our first neurologist who was awful. He obviously had no clue and was rather rude about it to the point of making her cry. We finally ended up at one of the best hospitals in Boston with a team of neurologists. The process was heartbreaking because the patient must go through behavioral and physiological exams which make them feel bad because they usually can't do simple things or become overwhelmed. We were always in the room with her except when she got scans or MRI's. Finally, after reviews of the tests & scans, the diagnosis was in, "Pick's Disease". I will never forget that day sitting in the doctor's office with my dad. We never heard of this disease. That's when I began to research – thank God for the Internet!

We took her for acupuncture, to an herbalist, whatever we could find, but nothing helped. She tried all the latest drugs including Aricept, but no luck. The symptoms became worse; she started having terrible hallucinations and had to be placed on Seroquel. This did help, but was very strong and made her sleep.

We kept Mary home for about five years while my dad and brother dedicated their lives to staying with her 7x24. I had a 2 year old and worked so my time there was limited to weekends. We worked as a team and did all we could to cherish the time, but it is hard work – you really should have help so that caretakers are given a break. When she could no longer walk or stand, we were forced to place her in a nursing home; she's been there eight years. We are fortunate to have found a lovely home that is immaculate. We had to educate the staff on Pick's Disease, as they never heard of it.

Now Mary is in the advanced stages and has been on a puree diet for about five years. She hasn't spoken in about nine years, just a few words here and there. Her motor skills are completely gone. We dedicate ourselves to being her advocate and initiate conversations with the doctors and aids when we think something is wrong. We keep her safe and make suggestions for how to care for her. This has been the longest good-bye.

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