

Helen Daniels Story

I have been meaning to write this story for four years. It is my mother's story; or is it mine? I hope it can benefit others.

My mother, Mrs Mavis Roche (nee Walton) was in her late 70s when noticeable changes in her behaviour occurred, like falling backwards, difficulty taking food to her mouth and a marked lethargy and apathy. People were commenting: "She has had a stroke".

I pleaded with her GP to do further tests, which led to her being seen by a Neurologist. I am not sure to this day (6-7 years later) if I regret that visit or embrace the news.

"PSP" "What the hell is that?"

So began a long battle to get my mother the care she deserved

My step-father, Jack, had been a loving caring husband to Mum for over twenty-years, but he just couldn't accept her not being the person she was when they married. Jack and I went from home help to aged care (high care) in a couple of years.

We were constantly battling with ignorance. No one knew what PSP was. My mother had to endure indignity after indignity. The nurses assumed she had dementia and wouldn't know any difference. Her voice disappeared and she became more and more helpless.

I am a trained nurse myself and part of the tragedy was having to deal with my peers who were so ignorant of the illness and some who just did not want to know.

Each day guilt compounded upon guilt (and still does four years later). I felt that as a nurse I should have been able to do more, but I was not in a position to care for my mother. I drove 200 kilometres every weekend to visit and phoned 2 or 3 times a week. I would hang on the other end of the phone waiting to hear her voice say 'Hello', which would sometimes take Mum up to five minutes.

She endured the most heart-rending coughing and choking fits. Eventually they told me the only option was to fit a peg, it was that or choke or starve to death.

About four months later mother slipped into a coma and I never spoke to her again. She is at peace now, and Jack's ashes were also laid to rest four months earlier. My strength to battle through alone was given to me by my mother.

By: Helen Daniels, Qld