

No White Flags - The story of Helen Ferry a sporadic CJD Sufferer.

My Mum was a bright and bubbly 53-year-old who loved and lived life to the fullest. After raising five children, Mum began her working career late in life. She loved her job, which brought her into contact with people, her true passion. She would walk or ride her bike to work most days and return home, to enjoy a meal cooked by her loving and doting husband of 33 years. Together they would share the joys and the woes of their working day before Mum would retire to the couch with her mobile phone. She would settle in for her daily ritual of chatting to one of her five children who were scattered across Australia.

In November 2004, she began to experience back pain and numbness, somewhat similar to a bulging disc. She went to a GP, a physio, a chiropractor and then back to her GP, with no improvement. By her grandson's 1st birthday on the 2nd of December, (the same day as Mum and Dad's 33rd wedding anniversary), she was preoccupied and we thought, 'over concerned' with her 'back pain'. She loved and adored her only grandchild but at his 1st birthday, refrained from picking him up for fear she might further damage her back. This didn't stop her showering him with kisses and cuddles but you could see the pain in her eyes as she watched his aunts and uncles carry him around.

Throughout December her back pain worsened and the stiffness progressed down through her bottom and into her left leg. By Christmas we all knew it was no longer simply back pain. Mum was sick. There was a considerable difference in her demeanor. The woman, who once walked 5-6km's regularly, was struggling to reach the end of our road, roughly one kilometre. Mum knew something terrible was happening to her then but we refused to let her entertain these thoughts. We were sure we would soon find the answer and she would be well again in no time.

Late in December, Mum went to Canberra for her first specialist appointment. A number of us were by her side and as always, Dad was the stronghold. Seven adults and one thirteen-month-old baby squashed into a two-bedroom unit. A long series of MRI scans and other tests ensued, including a lumbar punch testing for CJD, which returned a negative result. Words like 'Cancer', 'Parkinson's', 'Multiple Sclerosis', and 'Motor Neurone Disease' were thrown around. With each test our hearts would sink and then rise as a negative result was returned and another horrible illness was struck off the list. We remember Dad saying, "*Well the good thing is we have ruled out a lot of the worst ones.*"

But a haze of confusion still hung around as Mum's symptoms progressed. The numbness moved up her back and down her left arm and an involuntary twitch begun in her left arm. Mum was scared, confused and embarrassed as she watched her limbs take on a mind of their own. Her speech became slower. It took her longer, not to formulate her words, but to say them and she became increasingly frustrated by this. Her diet reduced and she began to lose weight. But she was still 'Mum'. Her personality never changed.

By the end of a week of tests and treatment in Canberra, with no positive results and no answers, we traveled to the Royal Prince Alfred Hospital (RPA) in Sydney where she was

to be treated by a Professor of Neurology - the Head of RPA Neurology. Mum spent ten days there where another series of tests were carried out. Mum's fears rose and her ability to sleep declined as she worried through the nights. "No white flags" became our motto as we urged her not to let this thing beat her. The involuntary muscle movement progressed to her legs and she now was unable to walk unassisted.

On the 22 January, Dads birthday, we were finally given an answer to our questions, 'Cortico basal degeneration' - a slow degenerative disease of the brain. We were told that Mum had a maximum of six years to live and that she would be bedridden within two.

Later, Mum said that as early as December 2004, she would lie in bed awake at night and 'feel the disease pulsing through her veins'. She said she knew way back then that there was something seriously wrong with her. By the time they diagnosed her she was almost relieved and she could stop worrying.

We however, were shocked and devastated. The prognosis was unbearable for us to take. The Professor told us Mum would have been deteriorating slowly for the last 1-2 years. But we were left confused. It had been a quick but 'staged' takeover of her body, occurring over the last few months. It had moved from one limb to another in a segmented fashion whilst her mind had remained as alert as ever.

The Professor told us we were wrong and probably 'hadn't noticed her deterioration before now'. But the Professor was wrong, not us.

Mum was flown home via air ambulance and Dad busied himself planning the next 2 years of his life with his wife in a wheelchair. Holidays and wheelchair access renovations. He was set to make the next 6 years as easy and as special as he could. We children also returned to Bega. We were all in shock and needed time together and time with our beautiful Mum. Major decisions were made in that time - all based on the belief we had about 2 good years left with Mum before she would be bedridden.

At our youngest sister's 21st birthday on 8 February there was not a dry eye in the room as Mum insisted on speaking. She sat in a wheelchair with her family surrounding her and my brother fighting hard to discreetly hold down Mums twitching leg.

Afterwards, our family started to return to their respective homes and to their jobs believing we had another several years with our beautiful Mum. However Mum continued to deteriorate at the same pace, if not quicker, before our very eyes. She kept losing her balance and it now took two people to shower her. She was using a walking frame but that was quickly replaced by a fulltime wheelchair. The twitching and spasms became severe. Her arms stiffened and her hands became clenched. What was going on? The RPA had turned us away with an expert diagnosis and a prognosis of a slow deterioration over 2 years.

Much of our anguish was relieved after a chance visit to Bega by a neurologist, Dr Leo Davies. For the first time, we felt someone really listened to us and to Mum and took notice of Mum's rapid deterioration. He offered some possible alternatives to the disease and arranged for Mum to be flown back to RPA. He told us it was not good

enough for Mum to have been discharged earlier and promised she would not be discharged again "until we got to the bottom of this".

So amid more speculation about her sickness and the possibility of a wrong diagnosis and the faint hope that this might be something else, something curable, she was flown back to RPA in Sydney. The entire family followed. It took only a few days this time. About 6.00pm, one night Dr Davies entered Mum's room. The mood was cheery as Dad relayed a joke Mum had played on him the night before. The look on Dr Davies face stopped all conversation and made our hearts race. We children left the room leaving Mum and Dad to hear the news. It was confirmed Mum had Creutzfeldt Jakob Disease (CJD). Dr Davies said she had about two to three months left.

The next few weeks are a blur as Mum returned home to Bega Hospital and eventually to her own home. Her brother, a nurse, moved to Bega with us, to care for Mum. Nine adults and one small child lived under the same roof caring for our dying Mum, wife and sister. Each child took the opportunity to have private time with our Mum to care for her, hold her and comfort her as the symptoms of this horrible disease took over her body. She was finding it increasingly hard to speak and to swallow and she had this horrible sensation that she was falling. She would call out in fright. All we could do was comfort her and be by her side every moment. Her communication lessened every day but unlike many sporadic CJD sufferers, she knew who we were right to the end and she understood everything.

On 5 March 2005, two weeks after she had been diagnosed with CJD, six weeks after being given an incorrect prognosis of six years, Helen Ferry passed away in her own home and in the arms of her husband and her 5 children.

The roller coaster ride of CJD had lasted but a few months and had left a family reeling in its wake.