

Like all mums, my mum was the most amazing woman. She lived a selfless and compassionate life, spending the most of her life caring for others. Shelley (Sandra's daughter)

My Mum was the most amazing woman

Two weeks before mum's 21st birthday, her mother unexpectedly passed away. Instantly, mum's family expected her to take over her mother's role. Her grandmother also looked to mum for help and support. She would be running around for everyone else with no complaints or regards to herself.

As a kid growing up, I remember mum raising my brother and I and dragging us from our home in Croydon to my great-grandmothers house in North Melbourne every Thursday so that she could tend to her needs. Mum did this for about 25 years, all while raising her own family and working part time. Soon after it was my grandfather who needed help. For the next ten years mum went from Wantirna to Pascoe Vale every other day to help care for him.

Finally, it looked like mum and dad could care for themselves but it was not to be! At age 52, dad had his first big heart attack. This started a chain of health issues and eventually Dad needed full time care and supervision. After 10 years of ill health, dad passed away at age 62.

Finally, mum was free of caring for others and was ready to live her own life. **Her big bucket list must do was to visit Canada and Alaska. In September 2017, her first big dream came true.** Mum, my brother, nephew, myself and some close family friends made the one month trip. It was the trip of her life and I'm so glad that I was able to be there to help her fulfil the first of her many dreams.

Unfortunately, that was all she was able to do. She only had 3 years of putting herself first.

In June 2018, she noticed some weakness and muscle wastage in her right hand. Not too worried she eventually visited her GP who referred her to a neurologist to examine her carpel tunnel. Within the hour, we were shocked to learn that mum had MND.

Like anyone that has been touched by this disease, we felt like we had been hit in the face by a Mack truck and the future we were facing was very daunting.



After a life of caring for others, this was mum's worst nightmare. We always spoke openly with each other about any end of life needs. Even as a kid, I remember mum saying that if she ever was in a situation that required 'us kids to wipe her arse, I give you permission to pull the pin'. Suddenly this was her future.

Once diagnosed we contacted MND Victoria as we knew that mum, and the rest of us, would need help to get through the challenges we would be facing. The Association was a great help in so many ways.

Mum's MND journey was very quick. By October, she was no longer able to drive and was using a ventilator at night. In January 2018, I went to part time work so that I could be home with her more and by March, I had resigned completely to care for her full time. She hated this, she never wanted anyone to put their life on hold for her. She was a proud woman who even gualified for the Mexico City Olympics as a butterfly swimmer and was now needing full time care

Fortunately we did one last family trip to Phuket in April. We'd booked it before her MND diagnosis. I know mum dug very deep within herself to make that trip our last family memory.

By May, she was ventilator dependant full time, unable to move on her own and starting to choke on water. She was looking down the tunnel of being a 'prisoner in her own body' as she would say. Mum needed help just getting around and staying independent. MND Victoria were fantastic. They provided us with lots of equipment such as a wheelchair and electric riser chair all at no cost to us. We are all grateful for the help the Association gave us even though mum's progression was so quick.

With euthanasia becoming legal in Victoria on 19 June, she asked me to help look into her end of life options. This was the hardest thing for me to do. She was my mum, I didn't want her to die, but I knew what the future held and understood it was a life she

didn't want, not just for herself, but for us as well. We started her end of life journey together but the hoops and red tape around euthanasia was too much for mum. It was going to take too long. Fortunately for her, she had another choice. As she was now ventilator dependant full time, she made the decision to stop any medical treatment that was prolonging her life. This meant switching off her ventilator. After meeting with her medical team and VRSS staff a date was set. The doctors wanted to be sure she understood what she was asking. Mum's response was that this is the easiest decision she has ever made in her whole life. She had no doubt that this was the right decision for her.

On 25 June mum was admitted to hospital to have the ventilator withdrawn. I stayed with her and our last time together was spent watching movies. I have always loved travelling, it was my work and life. My bucket list was to visit every continent at least once and mum knew that. She made me promise her that I'd get to Antarctica, the last continent. She told me that it's ok to be selfish and do things for yourself. While you should always be there for those you love, don't waste your life on others. So I promised her that I would and get to Antarctica.

Mum passed away the next day, with her stepmother, son, nephew and me by her side.

That was it, rather than going back to work, I made the 'selfish' decision to fulfill my bedside promise to mum and get to Antarctica. I ended up planning a 3 month trip through Central America and ended with a 2 week trip to Antarctica. Six months after I made my promise to mum, I boarded the plane to start my journey.

I know mum was with me for my whole trip, and I know that she is proud of me. I'm sure she is now yelling at me to make a new bucket list!

Thank you for reading my story. MND Victoria provides so much care and support to families and they can only do this through the generosity of their dedicated supporters. This year it's even more crucial with the COVID-19 restrictions that this appeal raises the funds needed to continue delivering care and support so please give generously to this appeal.



Top Right to Left: My Jayven. Mum and myself.





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