



Christmas 2016



“ Well Sweetie, you can count on me, I’m with you for the long haul ”

My name is Barry Baker and I am 73 years old. I have enjoyed good health for about 71 years and have been married to my wonderful wife Carol for 47 years. We have four adult children and ten grandchildren. We have been greatly blessed, but now I have been diagnosed with Motor Neurone Disease.

What was my reaction when I got the diagnosis?

Well I was shocked and horrified like all people who get given this diagnosis. Carol and I had retired from a lifetime of farming and were planning to grow old together.

How did I know something was wrong?

One day while going for a walk, Carol noticed I was walking differently. My feet were making a lot more noise as I walked, slapping the ground, which later became quite obvious. I started to become quite wobbly on my feet and my balance was not good.

After seeing a few Neurologists and having many different tests, I was booked in to the Austin Hospital for a few days for many more tests. *It was around 4pm on the Friday when I was told there was no doubt that I had what 2 people in 100,000 get; Motor Neurone Disease. I had no family with me when I received this news as Carol had been looking after grandchildren and was coming to pick me up on Saturday.*





“ I promised when we married, it was for better or worse, for richer or poorer, in sickness and in health, to love and to cherish till death us do part. I intend to keep that promise because I love you so much. ”



MND is a devastating disease whose cause is unknown. There is no active treatment, no remission and no cure. Diagnosis can often take up to 12 months. I was told that the usual life span is 2 – 5 years after diagnosis and some terrible things will happen in that time, especially in the last 12 to 18 months, which I don't dwell on.

I didn't think it was fair to tell Carol the news on the phone, I wanted to tell her face to face, so we could hug and comfort each other. The Hospital Chaplain, who was a lovely lady, was a big help that night; we talked and prayed and cried together. Carol arrived on the Saturday morning.

I knew it would be a great shock when she heard that I had MND, but she was marvellous. After just a few minutes, when she allowed the shock and horror to sink in, she said,

"Well Sweetie, you can count on me, I'm with you for the long haul. I promised when we married, it was for better or worse, for richer or poorer; in sickness and in health, to love and to cherish till death us do part. I intend to keep that promise because I love you so much." What a wonderful woman God gave me! We certainly were made for each other.

That was back in June last year and I've been just gradually getting weaker in the legs and feet; but still able to get around on a walking frame at this stage. I'd been forced to sleep in my chair as I'd been having breathing difficulties but **thanks to MND Victoria I now have an adjustable bed which gives me a much better night's sleep and I have a little more energy to get through the day.** Lately I am finding weakness in my hands and fingers so it is good to know that my MND Advisor and the whole organisation is there to support me and provide access to equipment to help compensate for the losses I know I will face.

MND Victoria has been serving people with MND for 35 years and we have been greatly supported by everyone there. They are well trained, compassionate, caring and very helpful in all they do. Our MND Advisor, Eric, ran an Information Session at our home for our children and grandchildren – it was a difficult time for them, but we were so grateful that Eric was able to address all the family at once so that each heard the same message. **Eric does a great job and he is prepared to go the extra mile for all his clients.**

The equipment supplied by MND Victoria, at no cost to us, is greatly appreciated. Because MND is usually a rapidly progressing disease, equipment needs are high and ever changing. Although I've only received a few items from the Association, it's not unusual for someone with MND to have six or seven different items during their journey and this can become very expensive.

Unknown to Carol and myself, our wonderful son Scott, with much help from family and friends, was able to purchase an old taxi which was specially built to carry someone in a wheelchair. He is enjoying getting it back into shape with the help of many friends. Carol and I have been very overwhelmed by what has been happening behind the scenes.

Even when I have to use a wheelchair this vehicle will help us to get to appointments in Melbourne and enjoy family outings while I am still up to it.

I know that what lies ahead will be heart breaking for Carol, myself and our family but our faith will help us all get through.

Thanks to your past gift I'm able to sleep a little easier at night – please, at this time when gift giving is on everyone's mind, Carol and I ask you to consider giving the gift of a better quality of life to the 400 Victorians living with MND every day.

Thank you for taking the time to read my MND story.

Barry & Carol

Barry and Carol Baker