

IT IS WHAT IT IS !

Richard Charles Riggs

25 August 1952 – 27 January 2020

An insight into Richard's battle with Motor Neurone Disease



Richard was living a full life, enjoying family times at our property “Skippy Park” on the banks of the Namoi River near Manilla in New South Wales. His passion was teaching children in horse events. Over the years when work permitted he had been very active instructing children at Pony Club, enjoyed tent pegging and on two occasions travelled overseas with the Horseball movement. In more recent times was he was a member of the Manilla Lions Club. Although past retirement age, Richard wanted to continue to work for as long as physically possible and was working as an Allocator for Incitec Pivot , travelling each day to Gunnedah approximately an hour from home.

We first become aware that something was not quite right months before the initial and final confirmation diagnosis. We had no idea of the impact these subtle signs were leading to. Richard started to feel very tired which we put down to his age and the travelling to and from work. Next he had a painful shoulder with the pain not going away after many weeks, than he noticed he was having trouble using his right hand. Simple things like holding a pen and using the computer were becoming increasingly difficult. Originally he had had a doctor's appointment and he mentioned the sore shoulder but nothing much was thought of it. It wasn't until the use of his hand had become a real concern and after some further prompting from his daughter telling him that he needed to get back to the doctor that he gave in and went back. That was 23rd March 2019. It was this visit that the doctor noticed a slight movements of the nerves around Richard's shoulder. The doctor immediately organised an appointment with a Neurologist. Within a week our whole world began to change. It was like a whirlwind, there were numerous blood tests, CT scans, MRI's and visits to the relevant doctors. The local Neurologist referred us to a specialist in Sydney for a second opinion and Nerve Conduction Study, than it was what seemed to be a painfully long wait for the diagnosis of Motor Neurone Disease to be confirmed. We continued to have appointments with the Neurologist who initially advised the need to contact the Palliative Care Team who would be able to assist us. We immediately tried to get things into place.

With the diagnosis confirmed we decided to make the best of the time we had and accepted an invitation from friends to take a trip with the destination being Ayers Rock and all the places in between. We purchased a Mercedes Benz Sprinter from an acquaintance and set off on the trip of a lifetime, beginning on 5 July 2019 and returning home some 7000 kms later on 25 July 2019. We hardly had to do a thing other than drive, although we were relieved from that on a couple of occasions when our friends gave us a break for some of the way. Richard handled the travelling very well, but on the way home started to have difficulties sleeping in such a small bed so we happily spent the last two nights in a motel. These are memories never to be forgotten.

After our wonderful holiday, Richard continued to go to work but over the months as the disease took its toll he went to working part time at the office and part time working from home, then it was working from home with only occasional trips to the office before he gave his notice that he would finish work at the end of September 2019. We will be forever thankful that his employer and work colleagues were very understanding and worked with Richard to enable him to stay at work as long as possible. At this stage he needed not only the friendship but having something to occupy himself was very important to him.

Throughout the process, he lost the total use of his right hand and arm with the nerve pulsing becoming more and more predominant until eventually it moved to the other limbs of his body. At first the nerve pulsing was not very evident in the other limbs with the Neurologist only being able to pick it up, but this soon started to become obvious. The gradual deterioration led to him being very unsteady on his legs resulting in quite a few falls when he lost balance or his legs gave away. Luckily, when he had all but one fall there were people around to assist getting him up. The one fall that we were alone was one evening when Richard overbalanced and fell into a position that I was unable to get him up by myself, I had to ring a friend some 13 kms away to come and lift him up. The eventual need to being in a wheelchair was the next step. This became very important because it allowed Richard some freedom in that he was able to take himself out to the back verandah to enjoy his favourite pastime of having a beer and a smoke although somewhat limited while taking in the beautiful scenery overlooking the Namoi river watching the kangaroos coming up from having a drink, the odd echidna passing through or the many birds that visited. At that stage Richard was also still able to travel in our car to enjoy a brief outing or to go to Tamworth for Doctors appointments although it wasn't too long when the travelling became too much for him and started to take its toll.

As the disease progressed there were further changes, he went from being able to use a knife and fork to having to be fed, being able to hold a drink to having to use a straw, from being able to dress himself to allowing someone else to do it, having to have someone assist him shower and shave (I was not very good at that), being able to walk without assistance to a non-motorised wheelchair then eventually to a battery powered one, a different bed for comfort and extra support plus easier access in and out of bed and then the final indignity of needing the use of a lifter to get in and out of bed and eventually not getting out of bed at all. Transporting him had now become an issue as well, at first he was able to get in and out of our car with my help although somewhat cautiously, it soon became apparent that this was also another hurdle to overcome because it got that way that we needed two people to assist him so he did not fall. Despite our best efforts this was also becoming impossible as he was unable to move himself and we were not able to move him into the sitting position at all. We looked at other options such as buying a vehicle set up to transport a person in a wheelchair, community transport and the taxi service. For various reasons none of these things were viable.

Richard went into hospital on 6th November 2019 for a couple of days respite so that I could attend a Motor Neurone Association Link and Learn Workshop at Pokolbin. He never really was able to come home for any length of time after that and remained in the care of the wonderful Doctors and staff at the Manilla Hospital. Richard loved reading but eventually had to give this away because his hands could not hold a book anymore. A friend loaned Richard his collection of Talking Book CD's, this small gesture gave Richard so much pleasure and ended up being a great asset to block off any noise to allow him to drift off sleep easily. One of the most unmanageable symptoms was the pain that took over his right arm and hand, it was excruciating for him to move it or be touched. This pain eventually took over his left arm and hand as well. Richard has always felt the heat and very rarely wore a pullover or jacket, he nearly always slept with a fan or the air conditioner going. As MND took hold the heat from his body was incredible, he mostly could not stand to have his feet covered even with a sheet, the temperature between his arms and body when unable to move them was also a problem. The nurses placed a pillow between to support the each arm and hand but this wasn't working very well due to their size and covering. Realising the problem I purchased a long narrow bolster cushion to use and found it worked well, it did not take up much room in the bed and could be moved with ease. In the end we had four of these, one under each arm and one used under his neck and another under his knees. These were a godsend for Richard's comfort.

Up until a month before he passed away he was still able to use the battery powered wheel chair and was able take himself outside for some fresh air. It was the end of December when he found his "better hand" let him down completely and he was unable to use the control button on the wheel chair, this was devastating for him as he had lost his last bit in independence.

We were able to bring Richard home for his youngest daughter's birthday in December and again for Christmas. These occasions while good for everyone, they were very hard on Richard physically. I knew that when he went back after Christmas that he would never be able to come home to us ever again. This was very hard to accept.

The last month was particularly hard on everyone, the disease started to progress rapidly and despite the best of care it started to take its toll. It was too late to insert a "peg" for giving Richard nourishment. Richard couldn't move his arms and legs without aid, he was totally dependant on everyone and inevitably permanent pain medication. Richard also lost his ability to communicate with us, we had the benefit of him using his eyes by blinking for a short time but even that stopped. Of particular heartbreak for us was that we could not comfort him by holding his hand due to the pain it caused. Whilst sitting with him we were able to rub him lightly on the shoulder or run our fingers through his hair when talking to him, but sometimes we found that it was irritating him. He could not tell us verbally but movements in his face did. These weeks were horrendous for Richard and equally so for our family to watch and struggle come to terms with what was happening, I don't think we have ever felt so helpless. The one thing that will haunt me forever are my youngest daughter's words, "Mum, I can't even hold Dad's hand".

Richard's illness had a lasting effect on those around him, no more so than the staff at the Manilla Hospital. As Richard's time grew near, their one beautiful and final gesture was that we were asked to bring his "going away" clothes into them so that they could dress him before going to the funeral home. As they had got to know him well in the past months they wanted to do it themselves so that it wasn't done by a stranger.

Despite his determination and best efforts to defeat MND Richard passed away on 27th January 2020.

Richard tackled Motor Neurone Disease head on with the mindset that "It Is What It Is", he said that "he wasn't afraid of dying but it was what he had to leave behind". He fought a short but hard battle, and his strength in his fight was like no other, but he was determined to go out on his own terms and when he was ready not because someone said it was time to let go.

Richard's death is still very raw and the trauma we felt from his last days will take a long time to fade into the background as we try to move on with our lives. His story is a very personal for us and as I write I hope it helps to raise awareness and encourage people to continue to work towards find a cause and ultimately a cure for this insidious disease.

Things that come to mind now that it is all over:

- I am forever grateful of the friendships that have been afforded to our family, without their help Richard's battle would have been so much harder.
- The Motor Neurone Association of NSW has been great with their assistance and the provision of the different equipment needed Richard.
- The Motor Neurone Support Group at Tamworth was a great comfort, the first time we attended we walked in dragging our feet and on leaving came out with the knowledge that we were not alone.
- Throughout the process we continued to have appointments with the Neurologist who initially advised the need to contact the Palliative Care Team who would be able to assist us. Getting things into place was a long slow process, there is just not enough funding and people on the ground to allow this to happen in a timely process. It was months before the first appointment for the ACAT Assessment interview which was to be 11th September 2019 but Richard had a medical episode which it was initially thought that he had a stroke on the night of 9th September and was in hospital for nearly a week. The ACAT Assessment had to be rescheduled and on ringing to arrange a further appointment found that because we cancelled we were taken of the list and had to start the whole process again. The ACAT Assessment took months and despite recommendations that Richard was to be at the highest level, this never happened. We were eventually given some home help for Richard which was two hours per week and then whilst he was permanently in hospital I received a letter to say that he could access Level 3 care. Ironically, despite advice that we would be able to have the bathroom redone to make it more accessible for Richard at home, it would be at least some 18 months away. For Richard it was too little, too late. I am forever thankful for the assistance that we did get but it was nowhere near what was needed at the time. From our experience, as well as the staff at the Manilla Hospital, the Occupational Therapist Sam was brilliant and helped us no end, and the Palliative Care Nurse John was able to assist us in many ways as well as the Physiotherapist Luke at the Manilla Hospital, these people were a great help. I cannot thank these people enough.
- On 19th June 2019 it was confirmed that I had breast cancer. I had surgery on 13 August and commenced radiotherapy 26th September until 17th October. Towards the end of my treatment, Richard was starting to deteriorate further and we found that he was unable to continue to come with me and although we were able to organise friends to sit with him for some of those times on a couple of occasions I had to leave him at home alone which was not ideal at all. This added further stress on our family and if the ACAT system had been of more timely and in place it would have eased the situation somewhat and been really appreciated.

Financially:

- We were fortunate to have savings in the bank because the cost of MRI's, CT scans etc and Specialist Doctors were huge.
- I left work to look after Richard for as long as I could, I used up all of my holidays and sick leave allowances.
- Although we held out as long as we could we found that we had to go down the Centrelink road which is a situation we fortunately have been able to avoid previously because we have both always worked. This is the most confronting and overwhelming process I have ever had to go through. There was no continuity in giving advice and assistance. There is no case manager allocated to you, every time I went in there was another form to be completed with additional attachments needed. At last count I have had 7 visits.
- Richard wanted to work for as long as he could so did not access the Age Pension when he could have at 65, it was a great relief when he was able to have those payments come through. I have to wait until I am 66, my only option was to go on Newstart and was told I need to look for a job. (This was despite that I was turning 65 y.o. November 2019, I was still undergoing treatment for Cancer, lived at Manilla where there is little or no employment opportunities, and my husband was in hospital dying a little more each day before my eyes and needing my assistance most days due to the demands of MND).

My thoughts for other families who are dealing with MND:

- We live some 13 kms from the small town of Manilla which is 46kms from Tamworth. It would have been so much easier if we had lived in Tamworth to access the services that Richard needed because they are either very restricted, non-existent or not available to people who live out of major towns, but this meant leaving our home and after some discussion and no real understanding of how hard it was going to be we decided we wanted to keep things as normal as possible and stay at home where we loved to be.
- When applying for services, if you live out of town, be aware that the travelling cost is taken into account when services are allocated, the further the travel the less the care.
- There are many people who lack of understanding of MND, some of these will surprise you. We had a GP who had been Richard's doctor for many years and with us from the very beginning of this journey who refused to sign a generic form for Centrelink unless Richard attended his surgery. At that stage Richard was not well enough to do the travelling. Another example is the people who drive the taxi services that can be used for people in wheelchairs, they have no idea of how helpless a person feels when they are sitting in the back of a vehicle in their wheel chair. When they are travelling to fast or on a rough road it throws the person about and frightens them no end. A little consideration would be very helpful.
- Transport is not as easy as it seems. After transporting Richard for as long as we could we had to look at other alternatives:
 - . purchasing a vehicle set up to transport a person sitting in a wheelchair – there are very few vehicles available and some of these are very expensive. Watching Richard's

rapid deterioration it was not a viable alternative.

- . community transport – a driver is not always available when needed, especially in a small town. We had the benefit of this only once.
- . taxi services set up for wheel chair assisted people – very expensive. For the short term when the driver can sit and wait for the person attending an appointment was \$150.00, for something like Christmas when the person was dropped off one day and picked up a couple of days later the cost was \$300.00.