



# A RIDE TO REMEMBER.



2019

## A RIDE TO REMEMBER RETURNS

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@aridetoremember  
@thisisdementia\_au

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After riding from Uluru to Ballarat (2300km) in 14 days last September, we were able to raise close to \$40,000 and more importantly people were talking about dementia. This created much needed awareness and knowledge for young onset dementia and dementia.

The ride was meant to be a one off- A closing of a chapter, a journey of closure and a ride to honour my father Sam, who at 54 was diagnosed with young onset dementia and passed away 7 years later in 2017 at the age of 61. Before we even took our first pedal strokes, the word was quickly spreading, and the enormity of the journey we were undertaking and why we were doing it was having a significant impact on people. Our impact was phenomenal, through social media alone we were able to reach more than 50,000 people each week with our highly anticipated ride videos. We met and spoke to many people along the journey, hearing about their devastating experiences with dementia and how they have been directly or indirectly affected. This is because it resonated with so many people, everyone could relate, everyone had been impacted by dementia in varying ways, it should have been no surprise, dementia is the second leading cause of death Australia. Sadly, it is a disease that is not often talked about, not properly understood, and the cruel impact and nature of the disease not truly known.

How could this be a once off? Dementia doesn't have the well-known public figure it craves advocating on its behalf, but three everyday guys had reached hundreds of thousands of people and started to give dementia a face and a voice. I am truly committed to giving dementia the recognitions it so sorely needs. With this, not only will I be undertaking another gruelling ride, but I am going step further and have also started a non-for profit organisation, called 'This is Dementia'. My message has been constant, and this formulates its vision- Closing the knowledge gap in the community is key. If we create awareness, this gets people talking about dementia and helps to increase knowledge. If people then have the knowledge on what dementia is, what it does and how impacts the individual and the people around them, then they begin to understand how significant the gap is in both knowledge and infrastructure. That's when people understand and know how desperate the need is to close this gap and the meaningful funding comes.

We are in the process of setting up monthly lunches at local restaurants and movie sessions specifically for individuals with dementia and their carers, as much as we would love to solve dementia today, it's not a simple fix. So as well as getting people talking about dementia, it's important we continue to encourage and support those currently affected, giving them a sense of independency and self-worth as well as a network of understanding individuals going through the same challenges.

This year I will be riding the Mawson trail, 1,000km in 6 days. Not only will this again physically and mentally test me, but I will also be well out of my comfort zone, trading in my expertise on the road for much more challenging and difficult terrain that I am unfamiliar with. These epic journeys are always going to be incredibly challenging and testing, but that's what is so crucial and important to me. That's what Dad's last 6 years were like, so I think it is important that I am tested the same way during my journeys, being physically and mentally pushed at every turn. I look forward to again sharing this journey with you and encourage you to again jump onboard.

The money raise will go towards this is dementia, to help increase awareness and knowledge, as well as helping facilitate the local programs mentioned above. We will again work with Eyre House in Ballarat, a respite facility for young onset dementia patients, but this time helping to develop a master plan, a longer-term plan to create a state-of-the-art facility. The money raised will provide individuals and families much needed help and support.

All donations, big or small are very much appreciated. I look forward to sharing this ride with you  
#ARideToRemember

To read more of my story, as a carer for my dad and what we both went through during his decline, I have included my story below.

My Dad, 54, was living a busy, full and successful life when he unexpectedly became ill. He spent 3 weeks in hospital where he was initially diagnosed with pneumonia. Unfortunately the cause of his infection was never found and it spread quickly throughout his whole body causing irreversible extensive damage. We weren't terribly concerned at the time and considered ourselves lucky to still have him, as the doctors weren't sure he would survive.

I was 21 at the time and while completing my university exams spent long days and nights at his bedside. Eventually he was able to come home, but unfortunately as a shadow of the man that walked into hospital a few weeks previously. Dad was never able to work again but made the most of what he could do and looking back now, amazingly, never complained. The once athletic man now walked awkwardly, had short term memory deficit, and struggled with verbal fluency. He was very self-conscious and embarrassed by himself but soldiered on. Life went on for us all, and we adjusted until about three years later, it was devastatingly obvious Dad was declining. A series of investigations followed with a diagnosis of atypical young (or early) dementia.

Most dementia diagnosis have a slow, steady decline and a plateau point. Unfortunately for Dad young dementia is a very aggressive disease, this meant he required 24/7 care to do the most basic of tasks including clothing himself, showering, eating, even sitting. Simple living became difficult. His last three years were a tough battle.

Between my Mum, sisters and myself, we worked around the clock to keep him at home and out of care. A family member would always be there, balancing our everyday lives with work and children, to care for him full time. It's quite confronting having to feed, clothe and wash your Dad, especially with the relationship between a father and son. There were days where he had frequent falls and even nights when Mum would ring me at 2 or 3am because he had fallen out of bed and she needed my assistance.

A Dad is always someone you look up to as having incredible strength, both physically and mentally, and to see that stripped away in front of my eyes was especially hard to deal with. I could also tell how hard it was for Dad, the protector and provider of the family, a man that lived completely and utterly for his family, relying on us to live every day. All he ever lived for was making our lives as good as they could be - this is what made him the happiest.

Looking back, living through Dad's battle with young onset dementia, I have realised many things, but there are a few in particular that stand out. Dementia isn't a disease that just effects older people, yet that is often the perception. Dad was 54, strong fit and healthy and it eroded his cognitive and motor skills as well as his dignity. His memory and ability to communicate all deteriorated and small daily tasks like getting in the car, sitting down on a chair or walking through a door could sometimes take 5 or 10 minutes.

Secondly, how isolating the disease is, not just for Dad but for our family as well. As mentioned, it's incredibly confronting to watch and be around someone declining so rapidly, simple things like going to get a coffee with friends was so traumatising for Dad as he would not want to embarrass himself or others by spilling something or not being able to eat something properly. The simplest of family pleasures like holidays or outings were no longer possible. Friends and family finding his illness confronting stopped dropping in to visit or including us in social events. Although we had a strong and close knit support network that offered amazing help, that broader network did become a lot smaller.

I am not the only one going through a challenging personal experience, I consider myself lucky to have had 26 years with such an amazing man. But what would separate me from other people that are going through similar situations? I could sit back thinking how unlucky I was for losing a parent so young? And why Dad? Why me? Why our family? Or I could be proactive. I wanted the negative experiences and feelings from the last few years to mean something, and wondered what difference I could make. I wanted to raise awareness and change the common perceptions of dementia and for some good to come out of a really 'shitty' situation.