Intro to Dad

My name is Jo. I’ve been asked to speak as a young person who has had an experience of dementia. For a significant proportion of my life, I lived with a father who at first had short term memory problems, which then developed into Alzheimer’s. To get the obvious out of the way, I am now twenty. Dad did have me later in life – he was forty three. He then was diagnosed with Alzheimer’s when he was about fifty nine.

Before I talk about dad’s sufferings and decline though I want to spend a brief moment to describe dad before Alzheimer’s.

Ted Thompson was the son of a boat builder, growing up sailing boats and being on the water. He often worked for his father, getting skills in construction and artistry. He left home at 18 to study philosophy and political science at uni, but realizing a lack of jobs in both areas he went back and studied Psychology, and eventually completed a PhD. He was a lecturer in Psychology at UTAS for the rest of his professional life.

While he was working on his PhD, he married my mother, Rosina and had myself and my younger brother Luke. He was a caring and generous father to us. He also was a firmly religious man, and the Christian faith he shared with my mum, he passed on to Luke and I.

Disclaimer

I would like to acknowledge that the only contribution to this subject is my own personal story, and as every situation is different, so WAS my father’s relationship with his Alzheimer’s. As a disease which affects everyone slightly differently, and as everyone is different to begin with, anything I say is just our experience. No decline I talk about should be held as a fear to anguish over, no good moment should be held onto as hope, and no experience I mention should be assumed to be the same as anyone else in this room.

The only thing I can offer is to describe my father, my family, our experience and how we dealt with it.
Aim

I’m going to aim to give you an account of what happened to dad, externally and internally, while trying not to bog you down in detail. I also want to convey how the events affected us, affected dad and his personality. How it affected his friends, and our little ways of dealing with things.

Bike crash

In 2001, my Dad fell off his Bicycle on his way to work. He loved riding, and would use the commute to work on his bike as a time to mentally separate his work and home life. His work was often stressful. As a psych lecturer, he had to manage his student’s needs, while trying to find time for his real love – research.

This particular morning dad was coming up to what was already the most dangerous part in his ride. If you are unfamiliar with napoleon St, it has to be one of the steepest in Hobart. It is also narrow and gets blinding sun in the morning. Dad was coming down it as a car pulled out in front of him. The car then suddenly braked for some unseen road works ahead. Dad realised his breaks wouldn’t be quick enough. He threw himself off the bike and with force tumbled off the bike onto the footpath about a metre below the road. His crash wasn’t anyone’s fault.

In the instant that followed, he suffered mild concussion, an ambulance was called, and he eventually conceded to go to hospital for a checkup. At first he was insisting that he jump back on his bike so he could get to work.

At this stage my brother, Luke and I were oblivious to dad’s crash. Luke was six at the time and I was eight. Mum picked us up from school at the end of the day with the news, calmly getting to the point that he was ‘ok’.

The next couple of months were a blur of MRI scans and a couple of borehole operations. Fluid had developed on his brain, a standard thing for a doctor to deal with, but dad got frustrated by the amount of time he had to spend in and out of the hospital.
I remember after the crash, my grade 2 class wrote to him with designs of safer bicycles. He took great effort to write back individually to every person in the class, thanking them and commenting on their designs.

He was in many ways a driven man, who valued his work and his ability to work. But his professional life was the first to suffer from what seemed to appear as ever increasing short term memory problems.

**Short term memory loss and diagnosis**

It wasn’t long before dad developed noticeable short term memory loss. This was managed by careful use of his diary, but eventually the pressures of professional life in academia became too much and he reluctantly retired five years later.

This was of course a blessing in many ways. We all had much more time together as a family; dad was able to put himself to hobbies and became far less stressed. The memory problems were still a challenge though. Often dad would forget to pick Luke and I up from school, he’d tidy our rooms (he was a bit obsessive about tidyness), but then he would forget where he put our homework that was due that day. He would also tell the same jokes (that were never that good to start with) every night at dinner.

For the next couple of years we tried to do lots of things as a family, and yearly went on short holidays. I think mum always suspected the Alzheimer’s was on the way, if not there already, as dad was slowly becoming more dependent on us, though he hated it.

I remember one such holiday to Sydney; we were watching a ballet at the Sydney opera house and dad wandered off in a crowd. I noticed him go and followed him from a distance to keep an eye on him. He spotted me following him and apparently later became angry with mum, feeling as if we didn’t trust him. Looking back, even us, as his family didn’t know how to deal with him a lot of the time.

When I was in grade ten dad was finally diagnosed. It took a second opinion, as dad’s understanding of brain functioning and memory had meant he had
managed to trick a pass in the test the first doctor had given him – he was clearly very defensive about his condition. Once dad was diagnosed correctly by a second doctor, I later learned that he talked a lot about suicide with mum. By this time dad’s brother and mother had severe Alzheimer’s and dad must’ve been scared by that. It should also be mentioned here that all dad’s life he’d struggled with anxiety and depression. It was mainly managed by medication, but as he progressed, these conditions became more acute.

**Worst times at home**

There came a point when dad all of a sudden seemed to go downhill in severity, and in frequency of the declines. For a period dad was in the stage where he could only understand everything as the superficial perception he could muster in each present moment. If someone was being nice to him, they were a friend. If someone was doing housework they were some kind of carer. Everyone seemed to take on new roles. Mum was sometimes the person who took care of him, sometimes a new girlfriend or even a complete stranger. He could remember that his wife’s name was Rosina, so when he asked this apparent stranger her name and heard Rosina, it caused him a lot of confusion. You could see on his face that he was trying to put together the impossibility that they were indeed the same person.

I tried to help him understand who we were by deliberately referring to him as ‘dad’ frequently when we talked.

His life became a worry. He would often (sometimes with intervals of only ten minutes) have to ask mum about his finances, and work situation. So he became completely dependent on mum for any sense of wellbeing. This in turn became the hardest period for mum; struggling with the pressures of being a full time carer, while coping with the gradual shift of role in dad’s eyes.

I found it harder to explain who my brother and I were to him. At one point he told mum to “watch out for those lodgers and dodgers”. But he was far more comfortable talking to me than he would to a stranger. I think, though he lost his
sense of identity for all of us, somehow he always knew we were people he could trust.

**Luke**

I remember a time when my brother Luke was holding a small party at home, while mum had taken dad on holiday. I was sitting in a group of Luke’s friends, and offhandedly made a joke about dad’s dementia. There was a moment of stunned silence as I realised this was clearly news for all these people – Luke had kept Dad’s sickness hidden from even his closest friends. He approached me later after the party, angry and frustrated that I’d brought dementia up. I said that the dementia was nothing to be ashamed of, especially among the people you know best. He clearly disagreed, but couldn’t justify his feelings about it – the closest he got was, “no one wants to hear about your bad news”.

**Music**

As dad’s decline continued, I found myself spending more time with him as mum desperately needed short respites. I would always offer to take Dad out for coffee, but often he didn’t want to go. Instead of getting him out of the house I developed a routine of getting him some biscuits and dip, wine in as much moderation as possible, and putting on music for him. His response to the music was the most poignant. Despite having reached a point where our names were a struggle, he could remember the vast majority of the words to all the songs I played him. On top of reenergizing his brain, his mood would invariably lift, and he’d generally forget about what was usually irritating him. I would just sit with him, listening to the music too. He never learnt to play an instrument, but he really responded to music and in earlier days would sing along to CDs and do little dances.

I should make mention of my own music making here. I am in my second year of a Bachelor of Music in Composition at the Tasmanian Conservatorium of Music. It goes without saying that musicians and composers express themselves chiefly through their musical output. It’s hard to say whether this was true for me or not. I can say that when I was at Uni writing, I had a certain escapist persona I adopted
– immersed in ideas and concepts, which felt totally separate to life at home. And so I thought the relationship between the two was very minimal. In hindsight though, the music I wrote in the second half of that year was significantly darker than the first semester: a sinister violin duet, a setting of a poem from the point of view of a deceased, and a requiem. None of which I was conscious of at the time, but perhaps there was something going on which I didn’t pick up on at the time.

**Church**

As the Alzheimer’s progressed we started relying more heavily on our local church for support. Mum had two friends there who would come and be with dad for an hour or so every week to give mum a break, and most of the church knew to look out for him on a Sunday if he was wandering off or looked lost. Once mum had left dad in the car for five minutes in town, and he had tried to walk home. It was a church friend who had spotted him and helped us find him.

By this time I was working for the church, doing a traineeship in youth ministry, so I often got swamped with people asking me how mum and dad were going if they weren’t at church for some reason. The church environment was good though. There are a number of older women whose husbands had dementia, though it never seemed as severe as dad’s. Even still they had a lot of wisdom to share, which was particularly helpful as an insight to how mum was probably feeling.

**Roy Fagan**

Eventually mum got to the point where she allowed herself to be convinced to book dad into respite, from consultation with Alzheimer’s Association. What I didn’t realise at the time though, was that she made the booking with every intention of cancelling it in the days leading up to when dad would be admitted. I’m not actually entirely sure what changed her mind. I think it must’ve been just an overwhelming feeling of exhaustion. We later realised that we had coped with dad at home for a longer period than many. When he did finally go into a home,
his dementia was far more developed than all of the other people in the home with him.

At this point I’d been spending lots of time with dad, taking out for coffee a couple of times a week and spending most of my time at home sitting with him or keeping an eye on him. While this meant that I couldn’t give much time to the other things in my life, and they suffered accordingly, I still enjoyed spending time with dad – I could tell somehow he still felt very fond of me and appreciated my time. I reasoned it out that Alzheimer’s takes you back in time, so he’d go back to when mum was a friend or girlfriend, but I was never anything to him other than a son, so it was simpler for him to understand me.

The weekend before dad was admitted I wanted to take him out for coffee one last time, even if mum didn’t seem to need it. But even in this last 48 hours dad seemed to take another step in decline, and the whole weekend wouldn’t sit still to talk. So I tried a couple of times to chat to him, but his mind was in other places and he couldn’t focus on anything I said. It frustrated me and I felt like him going into a home wasn’t a big deal, since there was nothing left to lose.

So dad was admitted to a secure dementia unit for two weeks respite. With no discredit to the unit, dad only lasted there a matter of days. He had managed to get halfway over the fence before he was found. After several other escape efforts it was decided the unit was unsuitable for him. He was taken to the Jasmine Unit at Roy Fagan (a psycho-geriatric unit of the Royal Hobart hospital) by some friends as mum was having her own respite in Melbourne, and I had been unaware of the whole transferring situation.

The Jasmine Unit was deemed to be the only place for dad, as it dealt with detoxing people from alcohol and other addictions, while providing geriatric care. It is also had constant monitoring by a doctor, who could change medications on short notice.

I should clarify here, that dad had been ‘self-medicating’ with alcohol, to dull his senses and lessen his anxiety. He’d drunk wine regularly his whole life, but in the late stages of the Alzheimer’s had increasing drunk more. We’d tried watering
down his wine or buying non alcoholic, but he’d sniff it out. The main issue of this was when he went into the homes he suffered withdrawal from the alcohol which increased his anxiety. On top of this the doctors tried lowering his mood stabilizing medication, so the first week or so was very traumatic for him, which I’m sure heavily impacted his mental health.

I clearly remember the first time Mum and I visited Dad at Roy Fagan. Coming through the armed doors we could see dad shuffling around, unaware of our arrival. We spoke with hushed voices to the nurse, before going and saying hello to him. Whether it was because he wasn’t wearing his contact lenses, or because his brain had stopped registering sight, we had to speak to him directly before he would know we were there. As soon as we did though he recognised our voices instantly, looked at us directly in the eye, and suddenly all the memory problems of home were gone. He knew our name and exactly who we were. But the first thing he said was, “Oh good you’re here, let’s go home”. Which was pretty much the same every time we would go and see him.

That first time when we visited dad at Roy Fagan, because he was clearly very distressed, mum decided that the only way we were going to be able to leave him was to get one of the nurses to distract him while we left unnoticed. This really upset me. Having to deceive him and treat him in a way that I didn’t think was right made me feel... just really really bad. I felt really sorry for dad and felt like I was part of the problem.

This was emphasized one day when some old friends went to visit dad. They told us later that in a moment of clarity dad somehow managed to say, “It’s amazing to think I used to be a fully functioning human being”.

Mum and I decided that it would easier for us if we visited him together. Mum was good at doing things with dad, she had ‘rituals’ of putting on music and incense, feeding him nice food and giving him special hand rubs. It was better than when I used to just follow him shuffling around or try to talk to him. I’d try to make conversation but of course the one thing I never let myself ask was, ‘how are you?’ outside of this I’d help him sit down until he decided he wanted to get up again, walk in a circle and want to sit down again – that became pretty tiring.
Once he’d managed to get out into the garden, which he thought meant he’d escaped. I spent ten minutes following him around as he tried to run along the fence looking for an exit. A couple of times he said to me, “we’re going around in circles aren’t we?” but he still kept trying.

Dad seemed to be in a state that was accurately described by the doctors as in psychic pain. His mind and body were out of sync, and his cognitive thought wasn’t up to what he needed to comprehend. His speech stopped making sense, and he kept using the wrong words for things.

Sometimes after leaving dad we’d go and have coffee to debrief. Roy Fagan felt so apart from the rest of the world it always took a little while to readjust. I felt like more of an outsider to the rest of the world in that period more than ever. While I never wanted to hide what was going on with dad, there were some people it wasn’t worth talking about with. For example I was playing it a rock band, and at rehearsal they’d ask me what I’d been up too. I was never in the mood to tell them the whole story and explain. The reality was though that spending time with dad had taken up almost my whole life, so I never had anything to talk to them about.

Church again became a great refuge here. Because everyone there had witnessed dad’s ongoing story, there wasn’t the need to explain everything all the time – which in some ways could become very wearisome. Interestingly mum found church the hardest to face, she said, “because everyone was so nice”. I think my best explanation is that because she didn’t have to (or couldn’t) put on a brave face to them, that she couldn’t fight back the tears and the pain.

In these most acute times of the disease, where mum and I were spending the most time with dad and least time with everything else, I had one of the most profound and strangest feelings of the entire experience, which later mum seemed to mirror. I felt like I wanted to clear up and get rid of all the ‘junk’ in my life. For mum, when it came later, that was a very literal feeling of wanting to throw out old paper work and tidy the house. For me it was a virtual tidying. I deleted my Facebook and Twitter accounts, deleted one of my email accounts and threw out one of the sim cards I had for my phone. Of course in doing so I
distanced a lot of people, and the vague half interaction you have with people on social media was lost. Left were only the half a dozen friends who I had a genuine relationship with. I haven’t actually gone back...

Death

We had always known of the ultimate conclusion of dementia, and it had got to the point where the doctors told us that Dad probably wouldn’t make Christmas. His high level of medications, along with the stress of being put into the unit had triggered a rapid decline, and he started no longer being interested in food. Everything ended up happening much faster than expected. One night, mum and I arrived for a visit, and found him shaking on the floor of his bedroom. The fit was a symptom of a stroke which had probably been the side effect of the medications.

After this Dad’s functioning dropped dramatically again and we knew that time was running out. He stopped talking, and spent most of the time in a medically induced sleep.

We knew that this was the time to say goodbye.

Mum and I spent as much time with him as possible. Mum slept there once or twice, and I remember racing off to bring Luke there. One of the ugliest feelings happened then; I became upset with Luke for not spending more time with dad. Luke was in the middle of his grade 12 end of year exams. While there was the option for him to postpone or not to attend the exam at all, he was determined to do it. I think there was some self consciousness even embarrassment in his behaviour, but he just genuinely wanted to keep things going and not have to keep the world on hold. I realised I was being unfair when I overheard a phone conversation between Luke and mum about how he felt I was judging him. I apologized soon after.

It did raise the question though, is the final moments of a person’s life any more precious than the rest of it? Following Luke’s example, in the end I decided they weren’t. That’s not to say mum and I didn’t try to be there anyway.
He had the stroke on Saturday night, then at 11pm on Tuesday the 20th of November, at the age of 62, my dad finally finished living.

Lessons Learnt

Coming away from the whole experience there’s been a couple of things I’ve learnt and realised.

I used to see death as the pinnacle of suffering – that all suffering should be avoided, and death primarily so. Seeing dad die was in some ways one of the easier events – compared to the exhaustion and stress of caring for him, the grief of seeing him lose his friendships and having to leave him at Roy Fagan when he begged to come home. In some ways dad’s death was the end of suffering far more than the start of it – not just in his life but ours too.

Something I was surprised by in the weeks after dad’s death was the difference in reaction in mum’s friends and mine. Mum’s friends flocked our house with food and flowers as soon as dad died. They weren’t afraid to come to the house without having arranged anything, and for a while we always had company.

My friends on the other hand didn’t seem to know how to react at all. The evening after dad died, I took Luke to his college art exhibition, where one of my closest friends was too. I wanted to tell him one on one and didn’t get a chance to, so texted him what had happened later. He sent me a nice text back, but when we caught up for coffee later that week, it was like he hadn’t heard. In the same way other friends would at best say, “I heard your bad news”, look serious and then have nothing to say. I don’t hold it against them, but I learnt that clearly my generation is terrified and doesn’t know how to respond to death or grief. Again this isolated me for a while, but I consider it a great blessing that I was in the middle of a church which was able to talk about such things.

Christianity

My family knew that none of us go looking for painful times, good things can come from suffering. In suffering we gain perseverance, in perseverance, character, and in character hope. Ironically the hope is for a time beyond
suffering. To look forward to something better requires the understanding of the fallible nature of our lives – and strangely this was comforting. I felt humbled by Dad’s condition and was able to see more clearly the weaknesses in me. After all, everyone kept telling me how much I reminded them of him. This all came from my family’s understanding of life through our beliefs. And I found that worldview most comforting because it gave me the vision to be know there is more to life than the here and now.

**Conclusion**

So at the end of it all where are we left? The numbers of people with dementia and Alzheimer’s in Australia continue to rise, and there are many of those people here in this room. We also have carers here from the family home and from institutional care. And we have some doctors and academics. If I can leave you with one thing, even though I reiterate my own subjectivity which I said earlier; the biggest danger/ NEGATIVE (?) to come out of Alzheimer’s or dementia in some ways aren’t the symptoms. In my dad’s life, generally his memory wasn’t nearly as big an issue as isolation (for him and us), Dependence on others (which impacted them severely too), fear and anxiety, loss of dignity and eventually the inability to function in a normal human way on any level. These are the things that made our lives difficult and stressful. It became harder and harder to know how we could treat dad in a way that helped him with all these issues, that retained his dignity and sense of value and purpose.

However it has to be said, for all the difficulties, there were always positive things in our lives that have to be acknowledged. The support of friends; who were loyal and helpful throughout, the support from Alzheimer’s Association; providing respite and counseling, and the support from the hospital; caring for dad professionally and sensitively, keeping us informed always and using their skills and medication in the best interests for all of us.

Then there’s the support that are most relevant to this conference. From the innate creativity that is a resource for all aspects of life. Music and good food were the two main tools we utilized, as their own form of medicine. I think too often we think of arts like these as means to their own ends, as causes in
themselves. To view music (for example) not as something you practice so that you can play it better and more often, but as something you practice so that it can be a skill for living life as it should be lived, in education, entertainment or in our case therapy.

For this reason, and the shared experiences with dad, I’ve decided to head down a path towards a career in music therapy. I’ve realised its potential, and I’ve seen how it heightens people’s quality of life. I realise that it doesn’t really have the power to save someone’s life, but I’ve realised how preventing death is actually overrated. And so spending time with people in music seems the best thing I can offer.

In an ironic turn of events choosing this course has landed me where we began. A prerequisite to post graduate music therapy is to study at least a year’s worth of psychology – in the same lecture theatre my dad used to teach in. Had things have been different it could well have been him teaching me today. It’s not quite a following in his footsteps though. Some parts I love, but plenty I hate, and I find it difficult to the point of often wishing dad could help me write my essays. Still though, I get the privilege of continuing to get to know dad through doing it.

Even after he’s gone, the world he left behind speaks him volumes.