Commmittee on Aged Care

This is a document I wrote for a friend who asked for a document outlining my experiences with my Dad through the stages of dementia. I also included my feelings re the need for better facilities and a higher standard/ higher vision for Aged Care in Australia. I hope it will serve as a submission to your committee on Aged Care.

20 .03 2013

I was blessed to be brought up in a loving home with 5 siblings. My parents had migrated to Australia when my twin brother and I were only babies. Mum and Dad had a happy marriage and worked hard to make a good life for their kids.

Dad (John) was a truck driver and business manager, later in life he spent many hours volunteering his time helping to set up a Church based Aged Care facility to assist the elderly in his community, he organised bus trips for the elderly, he sang in choirs in Aged Care institutions, and worked hard in his Church.

He adored his children and grandchildren. He would love to take them out in the boat waterskiing or fishing, and he especially loved little babies.

Dad was a respected member of the community and was always the life of the party.

My Mum Alida died of breast cancer 20 years ago, my Dad remarried the year after to a lovely lady named Greta. They had a good life and enjoyed travelling in their motor home.

We first noticed something was not right with Dad through his driving. He seemed to lack awareness. Because he was still driving buses we had to talk to him about it. He stopped driving for outings but continued still for a time with personal vehicles.

One incident not long after this was the beginning of his deterioration into dementia. He and Greta had booked a holiday which involved driving to Victoria where we were to meet them at a holiday resort for a few days. Dad seemed depressed. I had never seen him like this. Greta was really worried. Dad would not go out, he was fearful, and he talked morbidly about not being able to get back home. “You’ll have to take me home in a box” he said.

I decided to spend time with him trying to get him out. I succeeded in getting him to join me in a game of mini golf and eventually persuaded him to come on a half day outing. He started to come right and they got back to Tassie. It was hard to work out what had happened to him. Perhaps for a man who was always so in control he had started to he feel he was forgetting things, doubted himself and got himself into depression? Or perhaps became fearful of not being able to do things and had a prolonged panic attack?

The doctor prescribed an antidepressant. Dad had a few more of these episodes as the years went by but nothing as serious.

But he was starting to lose his memory and soon he was needing help with everyday tasks.

He underwent tests and was diagnosed with Alzheimers disease.

The way this affected me was firstly sadness. Dad was changing and becoming dependent. I couldn’t get Dad to feel better about himself. He was forgetful and he knew it. At the time all I could do was reinforce my love and commitment for him and gently ease him along the way. Sometimes this was hard because he would be unreasonable, not understanding why things had to be done for him sometimes or why he needed help.

Particularly difficult was reasoning with him to hand in his licence to drive. He had been a professional driver. It was his life and his self worth. It took some time to convince him. His driving had gotten quite worrying. We didn’t want to have to forcefully take it from him.

Eventually he handed over his licence.

His wife Greta needed help too. She had health issues and phoned us often. At that time they lived in Snug and we at Kingston, a good 15 minutes away. We relied on Greta to keep us informed and I would have to be on call in case of emergency. A few times Greta had to be taken to hospital due to her heart condition. This meant a constant state of concern for me and living in Snug had isolated them.

The decision was made for them to move back to Kingston to be near family. I found them a house to rent. Our daughter Alison lived just behind the little house so she and her 2 children were very helpful. When they first moved in and Dad got over the initial disorientation he was still doing his gardening, walking to the shopping centre, and able to do some things for himself. It was small things he couldn’t do or remember, eg finding things, clothing choices, bank/money issues.

For me it meant working closely with Greta. Not interfering, being careful to come alongside and support. Learning what she wanted and always trying to include her in the decision making. We thought about the future. Nursing home? But Greta wanted to stay and care for Dad at home. She didn’t want to move in with us either, a choice we did offer but understandably she wanted to maintain independence.

At this stage we also needed someone to be family “coordinator” – a role I naturally fell into being the only daughter and having had training and experience with the elderly and dementia in my work. My brothers happily left the decision making to Greta & myself and then it was up to me keep everyone informed. This was really important so that there was some sort of coordinated plan that kept the rest of the family informed of any issues, updates and to get help in if we went away too. A few times we had family meetings when important issues arose.

Dad attended a fantastic day centre at this time. It gave all of us, especially Greta a break and meant we didn’t have to worry about him during these days. He enjoyed his days at the centre.

Dad deteriorated quickly at this time. He began to wander and was waking up disorientated at night, making things very difficult for Greta. I was often called to assist with situations.

Greta needed to go to Sydney to a grandson's wedding so I organised respite care at a nearby aged care institution that Dad had helped set up.

This meant arranging an aged care assessment. He was assessed as low care but by the time he went to respite and during his time there he was assessed as high care. He had a respite room in low care but He had started to wander into other people's rooms and was disorientated.

At this time The Hostel advised us they had a place for him in high care. I went to have a look there and was distraught. It was a tiny wing, very plain like a hospital ward. No carpet, big white security doors that were shut after 2pm, small rooms and no activities.

I was in a state of shock when I looked around and just cried. We didn't feel it was quite time yet for Dad to move into a facility but the Hostel was putting on pressure - as these places do -because they have to fill the rooms quickly and they seem to pressure families by implying that if the room is refused at the time you may not be given a chance so easily down the track. That was a scary option. If Dad had to go somewhere we only wanted him at this place. He had been instrumental in setting it up after all.

I was talked around, the decision was made and we tried to make the best of it by visiting as much as possible. Because I felt so strongly the place was sub- standard dementia care I also took him out often. He attended his beloved men's group at his church till the week he became bedridden three years later. I took him home to Greta or to my place often or we would go down to the beach to his favourite icecream shop.

Not long after Dad got to the institution the place deteriorated. The large security doors that had been open till 2pm now were kept locked by code 24/7. The residents were like prisoners and they often banged on the doors. The windows in their rooms were only allowed to be open a few inches. There was absolutely no garden for them to look at, no lovely outdoor area. Not a blade of grass. Just a cramped ward with demented people. At first this was very distressing for Dad who always wanted to help people. He couldn't rest. All these people were calling out or coming into his room, and he into theirs.

There were no activities and the only time these people saw "normality" was at lunchtime when they were taken to the dining room.

Not long after this the nurses decided that these dementia residents would eat better in their own little kitchen in their own wing. Maybe so I argued, but there are enough carers in the dining room to help them and other nursing homes have no problem taking their dementia clients to the dining room. It was their only interaction with the other people and staff, a semblance of normality. I was assured it had nothing to do with keeping normal people away from those with dementia. No matter how hard I lobbied (talking to nurse managers, business manager,writing to the Board) nobody listened and the decision was made. Life changing and sad. Just one decision but so retrograde.

We had to cope with all these changes.

When I queried all of this for the umpteenth time the Hostel invited in an assessor from an Aged Care Team.

According to recommendations the Hostel did put into place an activities program. There were now activities but the residents still had no interaction outside of their tiny wing. I believe this “locked in, no real contact with normality” life contributes hugely to deterioration in many of these people. A person with early onset dementia living 24/7 with a group of other demented people?? Would you want to be in this position? It would drive anyone to dementia!

This was by far the hardest part of dealing with Dad’s dementia. Being **helpless** to get him better care. We couldn’t move him anymore. Soon he didn’t even know the dilemma anymore, but all of us sure did, and I still grieve so much now that in this day and age better care was not provided for dementia clients at the Hostel. The carers were lovely but the facility was and still is severely lacking.

The only trump we still had left there was that our daughter worked at the hostel and Dad loved seeing her regularly especially saying hello in the mornings.

But the Hostel decided that family should not work with family members although there had never been an issue or any complaint. This was an awful time. Dad was missing his granddaughter and it all felt very unfair. Looking back it was very unfair. I am still talking to and writing to the Board and will continue to write and meet with them until I believe they have improved their facility.

I still took Dad out till the week before he had a huge seizure and died not long after. He was almost impossible to get into the car, but we knew he was benefitting from the excursions. The hostel deemed it too difficult to take Dad on outings in the bus unless we came along. With our work commitments this was not possible and I knew the staff were just not keen to take him or anyone else from that dementia wing. There were few understanding committed staff to provide the best for these residents. Efforts were put into lower care residents.

Physically Dad was always well and very strong (except for one incident) but he could not control arm movements and definitely had no idea at all of what was going on around him. Dressing him was nigh on impossible for the staff. In the end times he needed full continence care so this was difficult when we had him out.

His son died during this time too but he never knew that. He didn’t (couldn’t) come to the funeral so I made sure we honoured his place as father at the funeral of his son.

Another distressing incident involved Dad’s doctor when our otherwise healthy Dad was diagnosed with gallstones.

His doctor advised to not treat him. He said Dad was old, demented and wouldn’t cope. We sought a second opinion having been told by Dad’s doctor that Dad would probably only have weeks to live. At that stage he was going well in every other way. Loving his family, loving his outings and smiley and responsive. We were very upset. My brother suggested calling his surgeon which I did straight away. He asked me to bring Dad the very next morning. I did, and the surgeon admitted Dad immediately, removing the gall bladder that afternoon. I stayed with Dad the whole time. The night was horrendous not because Dad was in pain but because he was disoriented and wanting to get up all night!

The **surgeon** was outraged that this lovely old man would have been left to die a particularly painful death with something as simple as gallstones. He said Dad would have probably been admitted to hospital in extreme pain and would have had to undergo emergency surgery that may not have been successful, who would want that for their family member?

I think the need for better aged care is screamingly necessary.

My experiences with my Dad through his illness highlight the fact that more dementia understanding and support is needed.

We as Dad's children needed to be there for our Dad but also importantly we really needed to learn those skills that cannot be passed on by hearsay only. How do you learn how to get someone to do things when they don't understand the process? How do you make conversation with someone who can't verbalise much in return? How do you promote physical fitness, community interaction or general well being with people who have lost the ability to self initiate?

These are all skills we needed to learn. Support in this area was useful, but some of the skills come from the experience itself of caring. Older people are valuable. Caring for them is also very valuable and as it should be in society. They have put so much into their families, their communities, their work, churches etc**.**

It should be a time they are being spoilt, offered great experiences and most of all honoured.

By the time they get into a nursing home they have often lost a partner, lost mobility, lost their home, lost memory. They are often depressed or grieving. How can we abandon them to "the system" that is sorely lacking. They are really worth the effort and money to make their lives happier. They are **WORTH** it. How would we like to be treated at the end of our lives?

We should be promoting a value of care for the elderly and people with disabilities too. A culture of dignity in life.

These are all thoughts that have cemented in my mind over the last years caring for my Dad.

Dad passed away a few months ago. He was 80 years old and very loved.