

## Senate Committee into Care of the Elderley, specifically those with Dementia

Dear Committee members,

I am very interested to talk to you and explain a) what I have experienced as a carer, b) what I believe should be the way we care for the elderly, especially those with Dementia and especially the Problem kind of Dementia and c) to tell you of two personal experiences with care in regard to how it was provided to residents of three different Nursing homes and one instance of community care.

In March 2000 I was diagnosed with Multiple Sclerosis, was so ill that I could not care for my children as I had always done, and my husband of the time had to give up work for a little while. After the initial 14 months of continual hits with exacerbations, I was hit with the big one (cognitive impairment); this was not unlike what I have since experienced with people with Dementia. To this day I remember how I was set up to fail at tasks, talked to in riddles so that others would benefit from the confusion they inflicted on me and the hurtful things that people did without even being aware of what they were doing.

After I recovered from this exacerbation, [REDACTED] went back to school to gain my Certificate III in Aged and Community Care so that I had the ability to earn an income now that I was on my own with three small children to care for. I attended work placement at the ADARDS Nursing Home caring for those with Dementia, something that I believed that I had a great empathy for given the Cognitive problems I had suffered twelve months before. I worked there for three years before the Nursing Home was forcibly taken over by a standard residential aged care provider due to the financial difficulty it came under after then Health Minister Lara Giddings withdrew funding of up \$220k per year if there was a shortfall in the runnign costs of the home and the funding from the Commonwealth. During this time, the Board of Management held a meeting with staff to inform them what was going on. At one of these meetings I raised my hand and asked the Head of the Board, Mr Tony Kilpatrick, in an election year, why were we not asking everyone that would listen for extra funds? I was told that we could not do this as we did not want to be seen to be failing. I replied that we were not failing in our care of the Residents, merely the ability to keep afloat financially without the extra \$220k per year. I was told that we were NOT to talk to anyone about the financial issues within the home and the meeting shortly ended. Had I known then, what I know now, I would most certainly have emailed everyone I could think of to ask for financial help.

During this time of attempting to gain a permanent position in an aged care facility, I worked at a standard residential aged care facility, in a Community care role, ADARDS role And was also caring for an ageing grandfather. Although I was not getting a lot of paid work,

two or three short shifts per week, my little family, my grandfather and my own illness were enough to keep my head above water with regard to finances and health matters.

While working at Queen Victoria Nursing Home, I found the carers to rush the elderly far too much to the point of, when working over the Christmas period on Afternoon shifts, I made notes for the Director of Nursing. I had a meeting with her expressing my concerns e.g. elderly needing to be fed by carers having food shoved in their mouths even though they had swallowing difficulties, I was even told to hurry up while feeding one little lady who I was feeding at the speed she could eat, another old lady, when being put to bed having her legs pushed back up over her head as the carers could not be bothered removing the removable bed rail to put her into bed in a dignified manner as this would take too long, and staff talking very badly to those with Dementia (early stage); these residents had the insight to know that they were being spoken to badly so would act out in return. When the DON did not seem to want to believe this was happening in the Nursing home that she was kidding, I chose to resign my position there and left to spend more time when available at the ADARDS facility.

This little home was AWESOME, quiet, slow paced and very respectful of the needs/wants of the Residents. I was told that even though it was good still, it was nothing on what it used to be when being run by Allen Bester, the old DON. We were always able to enter the kitchen and get residents any requirement, fluid or nutrition wise and could sit with them at breakfast time enjoying a cup of tea/coffee and eating a piece of toast or bowl of cereal; this encouraged the Demented residents to eat as they would mimic what you were doing. Those that were able, read the newspaper and we would discuss the news. This was all after a calm morning routine of waking, showering and dressing at the resident's pace. We often engaged in walks around the garden, picking flowers, feeding the chooks or birds or just walking with each other in silence whatever the resident wanted to do to keep their happiness at a maximum level. This was THEIR home and we were to respect this fact above all else!

Women would have makeup applied if required and men would be shaved daily to keep the facial hair under control reducing the stress involved with whiskers too long and hurting when shaving. Those who did not want to shower were offered the option of a spa bath or a dermalux towel bath, whatever made them happy and caused the least amount of stress but still achieved the daily hygiene requirements. The other carer that you were working with in the house would assist, either with getting the resident to the spa OR looking after the other residents in the house while you took them for a nice relaxing bath.

After being taken over, staff levels were lowered and timeframes for things like what time a resident had to be sitting at the dining table for breakfast were introduced. The older, more experienced staff left and then we were faced with 'English as a Second language' carers

who were being paid for by the Federal or State Government. Not sure but it wasn't being paid for by the provider according to the non english speaking carers. This language barrier became really difficult for those with Dementia, most in the end stages; they were already confused when being given instructions and now they were faced with accents that they could not understand.

Fluid and Nutrition were limited to scheduled times of day, continence pad allocations were limited to three pads per resident per day and if you dared ask for another, extra pad, you had to do a lot of explaining "why" it was needed.

As someone with continence issues of my own, I would be mortified if I had to sit in a wet or soiled continence aide until there was a) time and b) equipment to change me.

When asking the provider of my grandfather's community care if he could be seen more often, the answer was NO as DVA would supposedly NOT allow it. It was not until after his death and leaving the care industry to work in the Hospital System with the Aged Services Southern Area Team, did I find out that DVA would have given him way more hours in his care package if asked for and it was suggested that the provider did not ask for extra as they did not have the staff to cover extra care and would therefore lose the DVA contract for his care ☹️ Eventually he was put into Calvary Hospital by DVA covering his healthcare and after three months of waiting we got him into a Nursing Home. We live on the Eastern Shore of Hobart and all that we asked for was either a nursing home on the Eastern Shore, or one in the Glenorchy area so that it was easy for family and friends to visit him; we ended up at Lower Sandy Bay. On visiting him one day, he was sitting in the lounge, morning tea was delivered to his chair and placed on a table beside him. He sat watching into space and I asked him if he wanted his cup of tea? He replied that he could not hold the cup without spilling it. I asked the staff for a more user friendly cup for him to have his drinks out of in the future but at that time I merely asked for a straw, held the cup for him and he drank his tea with ease. He was crying when he thanked me and told me that he had not had a drink since dinner the night before; that made 17 hours without fluid. I spat chips, and in the nicest possible way, tore the DON a new one and demanded that when left a drink that he at least be left with a straw to enable him to drink it. They complied but not very happily. Another time when visiting at dinner time, I entered to a commotion in the dining room which I recognised as my grandfather's voice. I growled at him and he apologised to the carer BUT I perfectly understood why he was complaining; he was being served canned baked beans and some buttered bread/toast for dinner. He was letting the carer know in no uncertain terms that he had NEVER eaten this "shit" in his life and his wife would never have thought of serving something like this up and calling it dinner! After he apologised to the carer delivering the meals I put him in my car and we went down to the local take away, I purchased some fish and chips for him, and we sat in the park at a bbq table and ate them off of the paper with a bit of tomato sauce, with his fingers! He was like a pig in poo, he was

so happy to just be able to eat something familiar and he took his merry old time eating it, 35 minutes from memory, it was getting cold anyway 😊 I took him back to the home, took him out for a cigarette and then changed him for bed, washing him, putting on fresh pj's and putting him under the covers. I kissed him goodnight and promised him that I would visit the next day, which I did. It was a 40+ minute drive from my home but the look on his face when I walked in the next day was THE BEST and made the long drive worthwhile. I got him a drink and fed him his lunch before I said goodbye for a couple of days. It broke my heart and, to this day, I wish with everythings I have, that I would have put my foot down harder with my father, his son, and brought him home to my house to care for him until he died.

I would love to talk to your committee and answer any questions that you have for me but would like to say that I am tired of 'lip service' when it comes to the care of those most in need. Something needs to be done and it needs to be done now! Before I require nursing care in the not too distant future 😞 At this stage, I hope like crazy that Euthanasia is legal prior to me requiring care as I would rather take my own life than put my family through what I have seen other family members go through watching the uncaring way that their loved one is cared for. There are still some very good caring carers out there but unfortunately when it comes to Dementia Care, book learnin' isn't ideal as it does not teach you HOW to handle real situations (I would like to demonstrate a couple of these to you with my fellow carer and friend/colleague in Dementia Care Tasmania) Glen Oldham. We believe that you will be shocked to see a couple of scenarios that we have faced in caring for the Dementia Sufferers in ADARDS. I believe that this demonstration will enlighten you to the specialised trained care needed in caring for Dementia sufferers.

In closing, I would like to add that Nursing Home Providers are, of course, going to say that there is nothing wrong with their provided care BUT, I am here to tell you that they are covering their own butts in order to retain their license to operate a facility. I might also add that the Accreditation Process is, I feel, a bit of a joke, as facilities are told in advance of an upcoming inspection by accreditors and then DONs are running around getting staff to 'fix' problems prior to the arrival of the accreditors. Wouldn't it be easier to have processes in place that require facilities to have this level of care and documentation control at ALL times, not just for accreditation. I do not believe that accreditations should be 'announced' but rather spot checks done at random times of the day/evening and different days each time, nothing predictable!

I believe that our group "Dementia Care Tasmania" has a solution to the problem of quality, calm, respectful care for those living with Dementia and needing 24hr care. We just need to get someone to speak to us and listen, really listen. We lost a world renown facility, taken on by Japan, Canada and I believe, Western Australia, but no longer have it in the state of Tasmania where it was developed. Time to step up Federal Health Ministers and talk to those of us who can tell you how it really is out there. I have given you three examples and

would like to talk, face to face, with you so that I can look into your eyes when speaking to you and also demonstrate the aforementioned examples to help you to understand.

Yours sincerely

**Kyla Mathers**