

My name is Jenny Potter, and I wish to make a submission to the Senate Inquiry for “Care and Management of Younger and Older Australians living with Dementia and Behavioural and Psychiatric Symptoms of Dementia.”

I have 10 years experience as a carer for my husband diagnosed with Alzheimer’s disease at the age of 55.

Through our journey we have experienced diagnosis, living with the disease at home for as long as possible while experiencing all types of community services, community packages, respite residential care facilities, acute care and behavioural issues and antipsychotic medications in the last 12 months of his life. I experienced my husband being both physically and chemically restrained in residential care. My husband passed away 8 months ago, after only 4 months of being placed in a residential care facility.

My submission is quite lengthy, but it is very difficult to put 10 years experience of living with Younger Onset dementia into print. I feel I have only scraped the surface in telling our story. Our journey gave us exposure to every aspect of dementia care from beginning to end, especially with Younger Onset dementia.

Thank you,
Jenny Potter,

“CARE AND MANAGEMENT OF YOUNGER AND OLDER AUSTRALIANS LIVING WITH DEMENTIA AND BEHAVIOURAL AND PSYCHOTIC SYMPTOMS”

In 2002 my husband was diagnosed with Younger Onset dementia at the age of 55. He had been made redundant at the time after 23 years of service with the Company that he worked for. Prior to the diagnosis he was looking for work, but with a diagnosis of dementia he was to never work again.

Diagnosis – for us it took about 3 months from when my husband admitted that there was a problem and that he needed to see a Doctor. I was already prepared with the information we needed to get a diagnosis, as I had been concerned about a few issues for about 12 months prior. As I worked in the medical field, I had approached a Doctor that I worked with regarding what to do if you were concerned about a family member with memory etc. I was given all the information, so when my husband admitted he needed to see the GP, I was prepared with exactly what we needed to do. We had to wait a couple of months to get in to a Specialist, but we were given a diagnosis as soon as all the scans and tests were done. The specialist did believe it would be depression, but the scans and tests proved it to be Alzheimer’s disease. My husband was placed on medication immediately, which we believed over the years slowed down the progression and gave us a good quality of life and time.

Living with the diagnosis in the community – we then had to find community services and support to assist my husband to have a great quality of life. 10 years ago there were no community services available for a 55 year old male. They were mainly for elderly females. I persevered with many phone calls and also made contact with Alzheimer’s SA. We joined a support group, found an agency that thought outside the square to support us with community services that were meaningful and enjoyable for my husband, and also found an enjoyable interest my husband could attend weekly through our Council. As we were in the early stages of the dementia, and I was still working part-time, this was all we needed initially.

As years went by and there was decline, I stopped work, and we also needed more support and different styles of respite. The young age was continuing to still be an issue, but there were still people prepared to think outside the square to support us. My husband was still at the low care stage, which did make it easier. We have never experienced such discrimination in all our life going through this journey with a diagnosis of Younger Onset dementia.

Age restrictions must be removed for people diagnosed with dementia.

As time went by, and due to us not having children in this State, I decided I should register with the Commonwealth Carers Respite Services in case I needed emergency respite. I had also realised that with needing more support, we would require a package. Both of these required an ACAT. The very first assessment was not successful as we were told we were too young. With support from Alz SA we found this to be untrue, and had to persevere. Of course, we had to wait until a package became available as there just are not enough packages in the community. Eventually we received the next step of a CACP’s package. I am still hearing today, that people are being told, that unless they want a placement in a residential care

facility, do not ring for an ACAT, as they are so undersourced they cannot do them. The assessment team are not even recommending people be assessed for respite, due to them not being able to cope with demand. This leaves very little hope for younger people.

The ACAT assessment process needs to be totally reviewed and resources put into it.

Respite - As time went on, my husband needed more meaningful and different varieties of supported interests and things to engage in. Also, different varieties of respite was needed, still at a low care level. When I hear the word respite, I feel there are so many types, one type for the person with dementia, which can be in the home or away. It can also be from a couple of hours, half day, whole day, overnight or many nights. It also **MUST BE** appropriate (age if Younger Onset), meaningful and dementia specific.

Then there is the respite for the carer of the person with dementia, which also needs to be helpful, supportive and meaningful to the carer. We found a fantastic respite model with Norman House (overnight stay model) and also Myrtle Cottage based on person-centred care – what a person CAN do! (day respite model only). We were very, very fortunate. Even now, there are just not enough respite cottages. One has just recently opened in the West called “Seasider” (day only) which is another great model that should be duplicated. Another issue is that there is hardly any respite available on weekends. The above are all low care facilities, I was only able to find one appropriate high care respite cottage with overnight stay and that was Ridgway House. They have a high care week once a month. Currently, they have 16 people on their list, so you can get a week’s respite once every 4 months.

There are some fantastic community Respite models around, but just not enough of them. High care is critical. The successful models should be duplicated.

Then there is the residential care Respite. I never used this type of respite until 8 years after my husband’s diagnosis, as I never felt leaving him in an Aged Care Facility for 2 weeks was appropriate in any way, **BUT I HAD NO CHOICE**. My husband also still had complete awareness and understanding, and he hated being left in a facility with Aged Care residents, away from his comfortable environment that he was so used to. I was very relieved that the first facility I did use, took my husband for only a week and not the forced 2 weeks that most of them do. Every time my husband went into Respite and I brought him home, he would have declined and would take 1-2 weeks to settle back down.

TO FIND PRE-BOOKED, HIGH CARE RESPITE, IN A MEMORY SUPPORT UNIT IN RESIDENTIAL CARE WAS VIRTUALLY IMPOSSIBLE.

In July/August 2011 (9 years after diagnosis) I was planning to have a Xmas with my family interstate, but I knew I could not take my husband, due to his level of high care, so I did an exercise to look at the Seniors Information List of High Care Residential Facilities, that took people for **RESPITE WITH DEMENTIA**. The listing showed 146 facilities (9780 beds) which covered North, South, East, West, Adelaide Hills and Fleurieu. There were 43 respite beds **BUT ONLY 10** respite beds that could be pre-booked in a High Care Dementia Unit.

I also went on to the Respite Vacancy Today High Care Listings :-
75 beds were available. 41 were in a share situation, which just was not appropriate for my husband. This left 34 singles available now (some don't pre-book – they are rooms that have become available until they can fill them). Of these 34 singles – 9 were mild dementia only, 6 were not secure, 1 was female only, 9 were no dementia, 3 were country (Kadina, Pt Broughton, Meningie), 2 were extra services, 1 was not listed in the DPS Guide to Aged Care – THIS LEFT 3 OUT OF 75 BEDS FOR HIGH CARE DEMENTIA SECURE EMERGENCY RESPITE.

CARERS CANNOT GET TO HAVE VERY MUCH NEEDED BREAKS WITH THIS PROCESS OF RESPITE. I AM ALSO VERY MUCH AWARE THAT COST STOPS MANY, MANY CARERS FROM TAKING RESPITE – THEY JUST CANNOT AFFORD IT. IN SO MANY INSTANCES IT IS ALSO NOT APPROPRIATE RESPITE.

Respite in Residential Care needs to be totally reviewed and many changes made with choices, flexibility and availability. An understanding of excellent dementia care and staff training must also be a priority for dignity in care.

Packages – For us to progress to an EACHD package through the Agency already supporting my husband, we had to wait 12 months for a package to be available. The agency had never been allocated any EACHD packages in the last round. It wasn't a case of them not having enough EACHD packages, but that they had never been allocated any. How does this support a person with dementia to progress through their decline with the accustomed support. We wanted to remain with the agency as my husband was so familiar and comfortable with the carers.

What I found extremely difficult with the EACHD package in the community for a High Care male with behavioural problems with dementia, was that the staff in the community were not experienced and trained enough for this level of care. In the community it is mainly focused at low level care.

There needs to be many more packages available in the community. There needs to be a high care level of carers with dementia and behavioural training.

Acute Care - I managed reasonably well for the first 9 years with appropriate support, then behaviours such as anxiety, agitation, overstimulation and minor incidences of anger started to creep in. I feel a lot was due to frustration, hating the indignity of the disease, and understanding everything that was happening and going on with this insidious disease. By now my husband could not speak, feed himself, needed full assistance with personal care, but he still knew who everyone was. We had a consult with his specialist, and due to behaviour it was decided to introduce medication to settle his agitation, anxiety etc. A very low dose antipsychotic was introduced. Within 2 weeks we ended up in Emergency, and he was admitted to Hospital for anger, and to try and resolve medication issues. Emergency Depts are NOT dementia friendly, but once he was through Emergency and admitted to the GEM Unit QEH, it was very different. During this Hospital stay, my husband was being assessed for his behaviour, to see whether he could come home, or whether he would go to a Nursing Home, wherever there was a vacancy, which could have been anywhere – in a ward, sharing a room, in any facility, without any choice. Also, if his behaviour was

diagnosed as “Delusional” he would have gone into the Mental Health System, and would have been sent to Glenside or Hampstead. Our family wanted to have the choice to place the husband, father, grandpa that we loved and cared about so much, in a facility that understood and cared about person centred care and dementia. We wanted a loving, kind, understanding, caring and supportive environment with dignity in care.

There were many challenges in Hospital due to my husband having dementia, but we were in a public hospital (QEH) with a GEM (Geriatric Evaluation and Management) Unit, and within the Unit there was a lovely secure area with about 8 individual rooms that accessed a lovely garden, which was so appropriate for my husband with dementia to get out and walk around in. I found out, that out of all our public hospitals in Adelaide, there were only 3 with GEM Units. The whole unit focuses extremely hard towards achieving dignity in care for people with dementia. The only criticism I would have is the amount of different staff all the time, which is so unsettling for a person with dementia. Familiarity and comfort is so very important with dementia.

I speak very highly of the GEM Unit at the QEH. They strive for Dignity in Care. Look at this model, and any others that are working exceptionally well, and commit to this type of care in all Hospitals. Change Emergency Departments to understand and commit to specialised care and areas for people with dementia. Commit to training of staff around dementia and behaviours.

Permanent Placement in Residential Care – After discharge from Hospital, I realised I had to start to look at Residential Care Facilities in preparation for permanent placement. What a nightmare of a process this turned out to be – it was just shocking. I was told I needed to put my husband’s name down at many facilities, so I started the arduous process of trying to look at facilities and submit the mountains of paperwork to each Care Facility – just to go on their waiting lists. I was angered by the residential care facilities that do not allow you to look at their facilities. Also every facility had different processes. I had the DPS Guide to Aged Care, but found that it did not relate the real picture. It did not tell me which were the private facilities, which cost a lot more. I wanted the not-for-profit facilities. The guide did not reflect the true picture on which were High or Low Care or Dementia Units. I had to physically make extreme amounts of phone calls to get the true answer. I was advised that I could get a Consultant to help me, and that they can get you in quicker, but on contacting two consultants it was going to cost \$880 for one and \$990 for the other. We did not have the money to pay this, and I believe it is grossly unfair for the people who cannot afford a Consultant. We had not had a main income for 10 years, nor my income for 8 years.

Eventually, I had submitted applications to 6 facilities, and I just had to wait until a bed became available. You are also advised to keep ringing each facility weekly, to let them know you are still interested in a bed!!!! How does a 24 hour 7 day a week high care carer manage this.

After 6 months, I was still waiting. Each day my caring role had just got harder and harder. I kept ringing the Agencies week after week, advising them of my urgency. I had been told all along that availability goes on need. These agencies had never

seen or met my husband, so I questioned, “how do they understand our need when they have never met us?” The answer I was given was, “We go by the ACAT”. As our ACAT had been done 18 months before (high care ACAT’s do not get reviewed under the latest system), and the dementia had declined to a point where the ACAT does not reflect the true current urgent need, how can my husband be assessed for current need correctly!!!! I was also aware, that if a bed became available, if there is someone in Hospital or living on their own, they will have priority over us, as their need is higher, and I can agree with this. What I do not agree with, is that when you think of the facilities that we had my husband’s name at, only having 10 high care dementia secure beds out of 62, 18 out of 57, 24 out of 147, 16 out of 80, 12 out of 100 etc., urgent placement was not working in our favour.

I broke down eventually, while waiting for a bed to become available. Only the day before I had been interviewed by a facility which had 2 beds available, only to be told “THEY BELIEVED THEY COULD NOT ACCEPT MY HUSBAND DUE TO BEHAVIOURAL PROBLEMS”. WHAT WAS I SUPPOSE TO DO?? Due to my breakdown, the facility agreed to try respite for a month to see how it worked out. After a couple of weeks the facility felt they could manage my husband, and at the 4 week mark, he was accepted permanently.

A complete review into all processes involving Placement into Residential Care. Rather than many, many individual processes, one central system would be so very much easier. To have a very open and honest system.

Behaviour and Antipsychotic Medications - As time passed with my husband in permanent care, his behaviour worsened. I believe he was angry at being taken away from his home and me. He could not tolerate the noise of living with 15 other residents in this facility, after living in such a quiet environment at home with me. Noise was a huge issue for him. There were care-workers that he just did not like. Those that were loud, not gentle, abrupt, and not understanding, he just could not tolerate. He hated the indignity of personal care. He got angrier and angrier and became more aggressive. The staff at the facility admitted, they did not know and were not trained in how to deal with my husband’s behaviour. Prior to entering the Nursing Home, we had made contact with the Dementia Behavioural and Management Services (DBMAS) at Alzheimer’s SA, so they came and assessed the situation in the Nursing Home. Training was offered to the facility. Also, due to his behaviour a GP kept being called, and he was just increasing medications to try to slow my husband down, but it did not work. Antipsychotic medications just seemed to make my husband worse and worse. I arrived one day, and my husband was physically restrained in a princess chair. He was going wild, to the end where he was tipping over the princess chair. They had to release him, as they feared he would hurt himself. The way he lashed out when he wasn’t happy, was to grab hold of your arm, when you were trying to do things with him. One day he broke the arm of the Enrolled Nurse. That weekend the GP was called in again, and this time he prescribed “Haloperidol”. He was now having one antipsychotic on top of another antipsychotic. My husband’s Memory Specialist had always told us, you never prescribed one antipsychotic on top of another. I was horrified to hear what the GP had done. On the Monday I immediately rang DBMAS, as they were in the process of trying to sort things out. They advised me Haloperidol was a BANNED medication at the QEH and The Repat Hospital, as it causes death!!!! All of this was

happening after only 7 weeks of my husband being permanently placed in Residential Care. DBMAS suggested to the GP that Haloperidol be ceased, and that my husband should be admitted into Hospital to try and sort out medications and behaviours. He went back to the GEM Unit under Dr Faisal Ibrahim, a Consultant Geriatrician who completely promotes Dignity in Care, is not in favour of antipsychotics and promotes Dementia Champions. When my husband was first assessed in Hospital, it was found that he had “Neuroleptic Malignant Syndrome” – Life threatening neurological disorder most often caused by an adverse reaction to antipsychotic drugs!!!! It is shown in raised white blood cell counts and destruction of muscle tissue, which Ralph had all the symptoms. The Hospital had to try and wean him off medications and re-establish appropriate medications. He remained in Hospital for two months. He returned to the Nursing Home with us being informed that he only had one to two months to live, but he only survived 9 days back in the Nursing Home before he passed away from dementia. Four days after returning to the Nursing Home he stopped swallowing, then walking and eventually passed away.

This whole experience for our family was horrendous and one that will remain with us for the rest of our life. No-one should have to endure this experience.

From my experience of Residential Care Facilities, Behaviours with Dementia and Antipsychotics, I have learnt staff in facilities do not have enough training for dementia or behaviours with dementia. We need Dementia Champions in Acute Care settings and Residential Care. I have seen a DVD by Teepa Snow entitled “The Art of Caregiving”. Teepa Snow is based in America, but she trains careworkers in the art of caregiving for people with dementia. If careworkers were to take on any of her teachings there would be great improvement. The amount of Agency Staff in the Nursing Home did not make me happy, and it was always very unsettling for my husband. Brief training of Careworkers in Aged Care from overseas is not suitable for dementia care. **I have heard recently of a couple of Nursing Homes trying to cut back to using only 15% of Agency Staff.**

WE HAVE TO ACHIEVE EXCELLENT STANDARDS WITH DIGNITY IN CARE FOR ALL PEOPLE WITH DEMENTIA, YOUNG AND OLD.

I totally support the QEH Gem Unit, Dr Faizal Ibrahim’s Dignity in Care Programme, Teepa Snow’s art of caregiving for people with dementia, highly trained Dementia Champion Careworkers and Nursing Staff, The Dementia Behavioural and Management Services model (DMAS) and dementia specific Residential Care Facilities. Alzheimer’s SA totally supported us for 10 years.

SPECIFICALLY LOOK AT ALL THE EXCELLENT MODELS IN EVERY ASPECT SPECIALISING IN DEMENTIA CARE IN EVERY FIELD.

THIS IS GOING TO NEED A MASSIVE INJECTION OF FUNDING.

Jenny Potter,