26/04/2012 Jenie

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(Dementia)
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To The Committee

My husband, Kym, was diagnosed with early onset Alzheimers approximately four years ago. The type of Alzheimers Kym suffers from is hereditary. His mother died from this disease at age 46 and his sister, aged 46, also passed away from it 18 months ago, Kym turned 45 on the 29th March.

Over the last few years Kym's health has deteriorated significantly. Five years ago Kym was a fully functional member of society. He was hard working, physically very fit and loved his family dearly. Kym now suffers from constant confusion, his speech is impaired and his ability to function on a daily basis is extremely limited. Kym has become withdrawn and can no longer perform basic day to day tasks.

I have two young children (16) and (13). Kym's illness has had a major effect on them as it would any child. I have also had a difficult time dealing with Kym's illness and all the emotional and financial struggles that come with it.

I managed to keep Kym at home for 2 years after his diagnosis after exhausting all avenues to gain more care at home. I hit brick walls constantly because of Kym’s young age, I was emotionally drained from trying to keep up with the responsibilities at home, also I could see the effect this was having on me and our children.

In March 2010 I decided that Kym had reached the stage where I can no longer provide adequate care for him at home. This was an extremely difficult and sad decision to make but one that had to be made for the wellbeing of my children.

Since making this decision, I feel I have continually been confronted by 'brick walls' and have been appalled by the systematic problems that exist.

I write to make you aware of the issues people in my situation have to face and seek your assistance to overcome these. They are as follows:

1. **Young people with dementia cannot access the same help at home services as older people.**
   I understand an ACAT (Aged Care Assessment Team) assessment can result in access of up to 17 hours per week of home services through EACH (Extended Age Care at Home) packages. People under 65 do not have access to this package thus making it more difficult to keep our loved ones at home.

2. **South Australia does not have a residential facility specifically dedicated to younger people.** After enquiring at several nursing homes in our area it became apparent that finding a suitable facility for Kym was not going to be an easy task. Many advised me they were not willing to accept Kym as a resident as they were unable to provide him with the care people his age required. There were so many issues that surfaced and because of Kym's age, we just didn't seem to fit any of the appropriate 'boxes' with the evolving level of the care I was trying to find for my husband, whether at home or in a residential facility. I wrote letters to various Government agencies asking for help & advice but was told constantly there was nothing that could be done. It seems not only do we have to face the fact our loved ones are terminally ill and deal with grief & loss on a regular basis, we then have to battle systems that do not provide us with the care needed to help families survive this disease.
   I had to make the difficult decision to place Kym in a nursing home with old people which made a very difficult situation even harder. I currently know of two aged care facilities that would be willing to accommodate younger people but because of lack of funding from the government they are unable to provide families like mine with the help and adequate services we require dealing with younger onset dementia.

3. **Nursing homes and respite facilities resist taking on younger people because their needs are greater.** This is because **y**oung people are more mobile and need constant stimulation unlike older people who would rather sit quietly. If more funding could be given to the respite and residential facilities this would enable them to provide the staff and activities required to meet the physical needs of younger people with dementia.

4. **Nursing homes cannot access funding to provide activities for younger people with Alzheimers.** DisabilitiesSA has a residential avoidance programme in place for younger people. This programme can not be accessed by residential facilities because Alzheimers is not considered to be an acquired brain injury. Alzheimers falls under domiciliary care but domiciliary care progammes are only for the elderly. There are no programmes for younger people that can be accessed except with brain injury.

5. **When people are placed into residential care community services cease immediately.** For example, Kym attended 'The Shed' twice a week when living at home. Once placed into a nursing home, Kym was no longer able to access this service. The funding for 'The Shed' is provided by NRCP funding (National Respite for Carers Programme). When Kym is in a residential facility, any funding for activities is taken from residential funding. Residential funding only covers activities held within the nursing home. It is very important for younger residents in nursing homes to be a part of the community, it helps them to be more active and provides them with the physical challenges they need. It would have been good if Kym could have kept accessing this service given the lack of activities for younger people in nursing homes.

In February 2009 a National Consumer Summit was held in Canberra and it was documented that approximately 10,000 people under the age of 65 had been diagnosed with dementia in Australia. According to Alzheimers SA 4% of people diagnosed with dementia is familial (hereditary). Diagnostic tools are constantly improving which has resulted in an increased number of people being diagnosed with this tragic disease. Alzheimers SA is now receiving a phone call approximately once a week from family members of young people who are displaying symptoms of dementia.

If something is not done to provide services for these younger people now then in the future Australia will have thousands of young people with nowhere to go. When Younger people are diagnose, the disease progresses faster than an elderly person with dementia. We discovered the gene that caused Kym's dementia produced proteins on his brain 3 times faster than the average dementia patient. I believe this to be an important factor in making governments realize that families dealing with younger onset dementia struggle with keeping up with the decline of their loved ones and the importance of having the services required easily available and accessible, there needs to be more awareness and more services put in place immediately. There should be a dedicated unit for young people with dementia.

A younger onset agency could also be put in place to oversee all other aged care agencies with help for younger people with dementia. I believe this would be the key to providing the right care for younger people either at home or in residential care.

Any assistance the government can provide would be greatly appreciated by families like mine and hundreds of others dealing with younger onset dementia. Respite facilities and nursing homes particularly need help now with funding as this will secure the staff and provide the activities and services needed for residents like Kym to be kept stimulated and physically challenged while in respite/residential care.

I am hoping this letter will provide governments with some insight to what families and sufferers have to deal with and the anxiety that we all suffer because of this disease.

Not only do I have to deal with the stress associated with Kym's disease but I have to worry about my children inheriting Alzheimers too. I feel I need to do everything I can to ensure changes are made to the inadequate system that currently exists, as I may have to relive this horrific experience in the future. It is my passion to continue the fight to raise awareness & see that governments will understand the flexibility required to help families in our position to be provided with the care & support we need, policy makers and service providers need to shift their thinking in terms of what Alzheimers is and who it affects.

Thank you for taking the time to read my letter I look forward to hearing the government’s response and hope my family’s unfortunate experience can make a difference.

Yours sincerely

Jenie