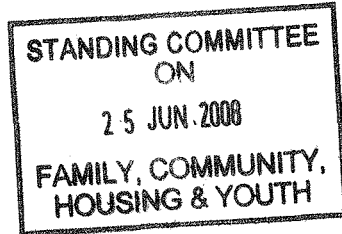


A.O.C. 4/7/08

Submission No. 360
(Inq into better support for carers)

June 22 2008



Secretary
Inquiry into Better Support for Carers
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
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Dear Secretary

My role as a carer is very challenging – particularly coping with the challenge on personal freedom and stability. If I had my time over again I would not take on looking after someone with dementia. If I had the choice of a jail sentence or looking after someone with dementia, with the knowledge I have now I would certainly choose the jail sentence. Whilst my freedom would be taken away in either, at least there would be something to look forward to after a certain given period of time for the jail sentence.

A friend of mine, who had over thirty years experience nursing in an aged nursing facility, believed that she was well prepared for caring for her husband when he was diagnosed with dementia. Now a year later, she is considering other options as the wear and tear on her is becoming too great. The 24-hour job of a carer, particularly for a person who is in later life themselves, is a massive task for which there seems at times little success and no reward, other than that of doing one's duty for a loved one.

I believe that, by looking after my aged mother with dementia at my own home, I contribute to society by saving the tax payers lots of money.

One way I believe this contribution could be given some recognition in the distribution of the will of the person being cared for. In my case, I will have done the work, whilst others who have not helped at this needy stage will receive the bulk of the inheritance via my mother's will. Her will had been made well before this situation eventuated and could not be changed after the dementia diagnosis.

My caring role affects my life socially mainly. Previous leisure pursuits, other than those that can be carried out at home, are no longer available to me – my boat sits gathering dust. We tend not to visit friends' homes as we feel more confident to support my mother at home (especially with toileting issues). Friends still visit our home providing important social contact for us, and my mother as well. My wife and I only have time out for dinner, or away for a day or on holidays, when we can organise overnight respite time via Blue Care, or longer periods via Commonwealth Carer

Resource Centre. I am almost totally tied to the house as my mother is less able to accompany me on even the simplest of trips.

I had retired from my previous work shortly before identifying the need for this caring role. As my wife continues to work I was able to undertake the carer role. If I had needed to work for financial reasons, looking after my mother at my home would not have been considered. Someone needs to be at home with her all the time for her own safety and security as well as the various appointments, provision of meals and general care. I am fortunate that my wife will be able to take sick leave to care for me, and my mother, when I require recuperation time after an operation. My wife's activities, both socially and professionally, are more restricted as she tries to limit her time away from home in order to provide extra support to me. At a time of life when we had hoped to be thinking of retirement plans, we are restricted - dependant on arrangements (made well in advance) that can be made for care of my mother. Spontaneity for activities, or changes in plans, is no longer available to us.

Looking after my mother does not affect me financially a great deal. I receive the carer allowance which generally supports fuel costs for attending appointments and such. The main financial concern relates to the issues I have in caring for her assets. I took on looking after my mother in the early stage of her dementia over two years ago, both physically and in terms of enduring power of attorney. At that time she had lived in a retirement village and needed to move to a nursing home. My mother chose to move to Queensland to live with my wife and me. The contract for the retirement village unit that she and my father (who passed away several years ago) had signed up for, was a great rip-off. If we wanted the total amount it was sold for, we would have had to wait eight years. To get the money at the time it was sold, to help get her settled in a granny unit built at my place and later a placement in a nursing home, she had to lose the equivalent of eight years' worth of interest. Now the money is in an investment account for her making interest. I use her pension for her living costs. Because the money from the sale of her home is earning interest, the pension amount is decreasing each time – even though the investment money is being built up to secure her placement in a nursing home. General living costs though are going up so in time her pension will not cover what is needed.

Looking after old people is not expensive in food lines but regular happenings such as leaving lights on, taps on, forgetting to turn off the television, requiring extra washing due to incontinence ... all means increased utility bills. As well as funding her living expenses, my mother's money is used to fund the occasional extra Blue Care respite – overnight and weekend. Without this I would not be able to continue my carer role as it would simply 'drive me nuts' and I would require care.

Friends of ours are in a similar situation looking after their mother/mother-in-law who is deemed legally blind. She has more funds in the bank than my mother but it seems there is no decrease in pension for blind people. This sounds discriminatory to me and I would urge the guidelines for different high-need medical conditions to be the same.

A practical measure that would help me as a carer is to be able to **access easier/closer parking at the busy local hospital, or to have the relevant tests**

for aged assessments done by my local doctor. Seeing the Aged Care specialist at the Base Hospital was a regular occurrence when my mother first arrived to live with us from Victoria. It is very difficult for me to get her into the hospital because of the parking situation. No-one is available to meet the aged person at a drop-off zone whilst I drive the car to find a park. Also I have had notification from our GP to bring my mother for an examination at his surgery. Visiting the GP is no problem as there is close parking and it is a short distance to walk in to the surgery. The nurse does all the regular blood pressure tests, urine tests etc. When the GP asked the memory test, it amazed me that it used the same questions and diagrams as the Aged Care specialist at the hospital. It would seem to me that it would be less imposition on taxpayer's money if the GP's test results were to be accepted for aged assessments. The GP can also refer to the hospital specialist. I am very pleased with the service and results of medications from the GP.

Another suggestion would be for the aged care specialist to visit the Blue Care centre to give these assessment tests whilst the aged person is visiting for respite. We will shortly have a person come from aged care visit our home to do an assessment by talking with my mother. I feel that if she spoke to the regular care providers at Blue Care this would provide a clear picture of the patient and their needs.

Another practical measure would be to **streamline the support services** so a new carer can more easily understand the system. When my mother first came to live with us we inquired about support services. It was difficult though to keep track of who was calling to discuss relevant matters because there were so many different groups and departments.

It is my experience with **Blue Care** that has been the 'saving grace' which has allowed me to survive so long in my carer role. The day respite services and extra respite options are so important and the staff has been very approachable and supportive. As well there have been morning teas and other gatherings for the carers to meet. Although I have not attended all sessions, I found these gatherings very helpful, particularly at first, to help get some perspective in my carer role – there's always someone worse off. The sharing of funny/sad/difficult/unusual stories by the other carers highlighted the experiences of others and helped me appreciate the relative difficulty of those in need of care. With my mother's dementia I feel as though I am under interrogation with the constant repetitive stream of questions that are not based in reality – this is mentally and emotionally exhausting. I 'take my hat off' to those who care at home for the severely physically disabled. That role must be physically draining as well as emotionally and mentally.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reading the recommendations that the group makes to improve support for the many valuable carers in our society.

Yours sincerely

Robert