

Submission No. 781

(Inq into better support for carers)

AOE 15/7/08

Sent: Monday, 30 June 2008 8:01 PM

To: Committee, FCHY (REPS)

Subject: Carer Submission

30th June 2008

Committee secretary,
Standing committee on Family, Community, Housing and Youth,
POBox 6021
House of Representatives,
Parliament House,
CANBERRA ACT 2600

Dear Secretary,

I am now 80 years old and have been a Carer for 12 years looking after my husband who has advanced Parkinsons" disease. I know my role is essential because he is entirely dependant on me and this is the only way he can receive 'one on one', care, which is impossible in the nursing homes, which are understaffed. I only tried once to give myself respite by leaving him in a nursing home, and decided "never again" There is not enough understanding of Parkinsons and the many various ways it can affect one. Although my husband has impaired speech, which makes it difficult for him to communicate, there is nothing wrong with his brain which is brighter than most. He is definitely not senile!

In fact the only remedy to most of the problems concerning Home Carers is to have a more well-paid, well trained working Force of Carers who help the community in the home and nursing homes. At the moment their pay is going to attract very few and in consequence there is an acute shortage. We are just lucky to have very good Carers (always the same ones, which is essential for my husband) coming to shower etc in the morning, but I know that others are not so fortunate.

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My social life has been practically nil because it is impossible to leave my husband alone. Although he has been on 'Each Package' for some years now, the hours spare for a Carer to come to be with him, so that I could get out, were three, which allowed me to dash out to do all the week's shopping, pay bills and see to other business locally. Even so it was only possible in an afternoon as no

carer was available in the mornings, and in the heat of summer that was not the ideal time. In fact at my age, usually, it would be the time to try and have a small rest while my husband had a siesta. I am up at 6.a.m. and get to bed at 11.30 p.m. and need some time off. I have had to rely on friends if I wish to go out. As my husband has deteriorated I cannot leave him with friends, so my family (none are in Canberra) have clubbed together and luckily found and paid for some private help so that I can get out in the morning to shop etc. We could not afford it ourselves. Others in my situation may not be so lucky.

Another aspect, which I find a worry, is that one cannot get a doctor to visit the home in the daytime. If my Husband is ill it is impossible for me to get him out of the house, and it is no good saying, "Call an ambulance," because unless he is actually dying he may sit in the Emergency for fourteen hours, as I did all night last year after being taken by ambulance, when I actually needed a specialist and nothing could be done. Apart from that he says he would rather die at home! I cannot see a remedy with the present lack of medical staff.

The other problem is finding a Carer to come at short notice to look after him if something happens to me. We have no family in Canberra and on the two occasions that I was taken to hospital I managed to get hold of my cleaning lady, who does know my husband's difficult routine with Parkinson's and can understand him. Later when I enquired around at all the Carer agencies I found there was no such service (ambulances are not going to wait) and one organisation suggested that maybe my husband could be taken in the ambulance too. Seeing he needs constant attention I don't think he could sit for hours in the waiting room with no-one to see to his needs. I know this is a difficult situation to remedy, as I cannot see many people willing to be available day and night, but others must have the same problem as me.

I suppose the problem stems again from the lack of staff and available care in the hospitals due to funding.

These are my main concerns to keep my husband in the home, as I shall never put him in a nursing home, in spite of the fact that I have suffered a heart attack and a fractured back as a result of caring for him.

Yours sincerely,

Pamela