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(Inq into better support for carers)
A.O.C. 30/6/08

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Committee Secretary,
Standing Committee on Family, community, Housing + Youth
PO Box 6021
House of Representatives
Parliament House
Canberra ACT 2600

STANDING COMMITTEE
ON
18 JUN 2008
FAMILY, COMMUNITY,
HOUSING & YOUTH

Dear Secretary:

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's inquiry into better support for Carers. I apologise for making a handwritten submission but I have no access to computer or e mail technology. I thank you for accepting same.

From early 2002 to late 2007 I was a full time carer for my husband who suffered from dementia. My experience is mainly in that regard but I have also at times contacted others in need with completely different problems.

My husband & I were both Age Pensioners.

I felt that my role was to keep my husband as content and healthy as possible. I chose to try to do this at home as with his no longer understanding the how, where & why, he would be distraught even angry with strange people in a strange place. Also it cost the government much less my way.
I had to give up all volunteer work and all participation in community events but perhaps I was making my contribution in this way.
I faced many problems. At all times my husband needed supervision - 24 hours a day. As my husband's illness progressed I found medical attention almost impossible. I could not Take him to a doctor's surgery and doctors became reluctant to make home calls - time consuming when they are already overworked. He was seldom physically ill but should have had more constan evaluation for correct prescription of his medication. It must be very hard for a GP

to assess changes + reactions to medication in an almost unknown patient with this disease I also needed support.

I became in need of + was able to access respite a few hours a week which did no more than cover household affairs + my medical + dental appointment needs. And later still Home Care was able to shower him daily, including using a hoist for transfers. I was eligible to access long term respite which may have been adequate except that I found it was not readily available and ~~that~~ staff did their best, but were overworked + sometimes, quite often, not specifically trained to deal with the patient's needs.

My husband + I had practically no social contacts during these years apart from the very infrequent visits from distant family, the visits from respite workers, and the times when it was possible to drive him to previously familiar haunts. No day care was available of any description for my husband. I had an occasional Carer's morning tea when my respite could be altered to suit. For which I was extremely grateful.

I was never able to participate in other social events because there was never the time + I did not really have the energy.

Now six months after my husband's death I find I still lack the energy, my health deteriorated markedly, and only now after I have myself paid for therapy is it improving.

Perhaps, the care of previous carers following the traumas they dealt with is also a big issue.

Transport for carers + their patients should also be available more freely. Taxis + public transport just are not there in very many areas.

We would have struggled much more financially if not for our own efforts. My husband paid taxes all his working life, while being the sole support of our family of six healthy young Australians. He also provided us with a small modest home and with thrift and having no expensive holidays etc we had some savings. We were both on an age pension + I had also carer's payments and we were eligible for some discounts. Community Care loaned us much needed equipment when necessary + as available but I used these savings for the other items I considered necessary for his comfort. Firstly the complete reconstruction of the bathroom in our home to hospital standard. The altering of the floor to allow hoist, bed + chair to run easily etc. These improvements were also necessary to attempt to lighten the load of the respite + care staff in their duties. Some assistance with finance may have been available from Govt Departments if I had been content to wait in line, but I rightly decided to go ahead as the need arose - later was too late.

The things that stressed me most about being a carer were the lack of enough enough support for myself in the amount of respite of a quality + quantity necessary to allow me to have some social outlet; for most of the time the lack of social contact suitably supervised for my husband; the

the scarcity of suitable respite for my husband when I felt my own health deteriorating, due to constant tension + lack of sleep; the lack of suitable transport was a big issue for others - only because I used savings to buy a small S/H car which family serviced + maintained, was I able to manage. Another stress is knowing that all care staff, of all levels, are overworked and are not able to do the work to the standard they would prefer. This is another great stress. Having to deal with the different departments + agencies was a further hassle when I was constantly stressed + overtired. Could like services at all levels of government be combined effectively; 'a one-stop-shop' established where queries of all kinds could be dealt with - at least the information of where to go given; and all of the above places of reference be known to all carers easily because quite often they just don't have the energy to continue their search.

Thank you for taking my views into consideration as part of the Committee's inquiry. I look forward to reviewing any recommendations you make to improve life for carers in Australia

Yours sincerely
Bee