

ADC 4/8/08

Committee Secretary

Inquiry into Better Support for Carers

House of Representatives standing Committee on Family

Community, Housing and Youth

PO Box 6021

CANBERRA ACT 2600

Submission No. 1163

(Inq into better support for carers)

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth Inquiry into Better Support for Carers.

I am submitting to the Inquiry because of my challenges as a Carer in the past 12 months. I feel frustrated by the "system" which I feel fails to deliver what it promises: in my opinion due to lack of adequate resources and confusion and inefficiency due to multiple service providers and lack of transparency.

I am 61 years old and care for my 76 year old husband who had a stroke in June '07. He also has Parkinsons Disease and Lewy Body Dementia, which has progressed in recent years. Residential and Day Centre respite services offered do not meet his needs, so my options to do anything other than look after him are restricted.

The Role and Contribution of Carers in Society:

I see my role as a carer to be **compulsory**—I don't have a real choice: My husband desperately wants to be at home and does not want to be in an aged care facility. I don't have a problem with this—after 38 years of marriage I am committed to supporting his wishes.

However my role as a carer is **costly**—I intended to work at least half time until at least 65. With my husband's deteriorating condition I stopped when I was 59. This means we don't have my wage and I can't contribute more to my superannuation as I had planned.

I can only strongly support all the research that the role is **stressful and super demanding at times**. I have never had physical or mental health issues in my life. I do now!

The Barriers to Social and Economic Participation for Carers:

I am **isolated from previous co-workers**—social contact with them was an important part of my life. I could not return to my old occupation as I am now two and a half years out of date!

Different, less skilled **paid work or volunteer work is not an option** because I can't make definite commitments due to my husband's fluctuating behaviour and high care needs.

Access to new social groups and activities is limited by availability of suitable respite care for my husband.

Visiting our children or relatives is severely restricted by lack of suitable respite care for my husband.

The Practical Measures Required to Better Support Carers

Simplify the Maze: When my husband had his stroke, the hospital social worker helped me apply for carer's allowance, obtain an "Advice for Carer's Package", organised a "Post Acute Care Program", and gave me information about "Home and Community Care Services". A month after my husband came home I was drowning in paperwork and information and going round in circles trying to find out who actually did what!

I got lost in "the maze" as I tried to work out who to contact for various types of support. I had to deal with: District Nursing Service and Cognitive Dementia and Memory Service - West Gippsland Health Care Group, Gippsland Regional Aged Care Assessment Service - Latrobe Community Health Services, Carer's Victoria, Baw Baw Home and Community Care, Commonwealth Carer Respite Centre and Commonwealth Carer Resource Centre, Centrelink, plus GPs, physician and Neurologist.

I found this very stressful. I believe if I had been able to continue with the support of the hospital social worker and if the local healthcare group co-ordinated the services I would not have "fallen in such a big heap".

Provide Counselling Services for new carers: By the time I sought help from my GP and was then diagnosed with depression due to stress and sleep deprivation we had reached crisis point. I could no longer function and needed professional help. The psychologist advised me that I needed urgent residential respite care for my husband or I would end up in hospital. I needed ongoing counselling for some time.

Provide Adequate Resources for Aged Care Assessment Services: Of the list of services on offer from ACAS all we have been offered is the "Completion of the assessment forms that are essential to access residential respite, residential care and certain community care packages". It took months to complete the ACAS process. In April 07 we received a letter accepting referral for assessment. It was mid November '07 before we had a letter advising us of the results of the assessment and that we would be contacted as soon as an aged care package was available.

I believe that this unacceptable time frame was because the human resources were simply not available. It meant that I had to care for my husband for months without support.

I refer you to carers Victoria "sheet 19-Series 1-Caring for an older person" for a description of services that we simply have not been offered.

Provide Adequate Resources for Residential Respite Care: When my GP and psychologist tried to organise emergency respite care, there wasn't any available for three weeks. This is not "emergency respite". If I had ended up in hospital with a nervous breakdown, who would have cared for my husband?

We have to book months ahead and I feel, compete for a very limited number of beds. Through a carers group I have recently met people, whose needs seem greater than mine.

My husband hates going into aged care facilities. His main complaint is that the staff are too busy looking after sicker permanent residents to help him, particularly at night. He reports waiting on the toilet for half an hour or having to sleep in a wet bed (Given his dementia, this may or may not be accurate). My own observation is that personal care is very limited compared with home. He also reports that he is bored and there is nothing for him to do. (Again this may be his perception and not true). It is difficult as a carer to benefit from respite knowing that my husband is distressed.

Respite when I need it, not when it is booked, in a specific place for respite dementia patients, with more staff and appropriate activities would better support me.

Provide Appropriate Dementia Specific Respite Day Programs and Diversional Therapy: We were offered and we accepted an EACHD package in December from yet another organisation based in Morwell-again outside our local area. This means that the service provider is not familiar with the local scene -my perception which may be wrong. I have asked for Dementia Specific Day Program or a Diversional Therapy Program, but the answer is nothing for my husband outside home.

We do have a set 11 hours per fortnight of in-home respite, which allows me to do shopping, banking, go to doctor, counsellor, carer support group or attend medical appointments with our 19 year old son who has ongoing medical issues. These are survival tasks, not social events.

I have also booked very limited care so I can attend special family events and more recently so I can meet new people in a social context.

I have only great praise for the workers who come. They are not provided with any resources to help them care for my husband. To their credit they bring their own DVDs, life stories and personalities to help my husband while I am away.

I feel that my husband would benefit if the workers were provided with dementia specific resources to help make their time together more enjoyable. It can't be good for the workers if all he wants to do is sleep! **I also believe that I could access more social groups or activities if there was an appropriate Dementia Day Program that he could attend.**

Make the Funding for Dementia Packages More Transparent. I have found it very difficult to work out what I am entitled to and have no idea whether the service provider is providing value for money. I am sure that I have read somewhere in the great morass of information that a "Dementia Package" equates to 17 hours respite per week. The service provider tells me that it equates to about \$80 per day, which has to cover all expenses, such as continence products, podiatry, aids, payments to other service providers etc. This leaves me with no idea whether my requests are reasonable or not, since I am not told the price of continence products or the real cost per hour of in house respite. \$80 per day = \$560 per week = \$14,560 per 26 weeks. In 6 months we have received 160 hours of in house respite care, 40 hours HACC in house care, and 1 week of residential respite care. The service provider has also paid for 4 podiatry appointments and has supplied continence pads and pants. I cannot believe that we have used our "budget", but have no way of knowing if more requests for respite are reasonable. **I would much more empowered if I was told directly the value of the package and received "account" details of the real cost of services provided. I could then plan for what I thought was best for me and my husband.**

Strategies to Assist Carers to Access the Same Range of Opportunities and Choices as the Wider Community:

I feel that as an older carer of a husband with progressive terminal conditions, I accept that I cannot participate in the wider community as I had planned. If I could access more respite care, then I could engage in more social / sport or self education activities.

Maybe I could retrain and do some home computer based work, while I care for him?

If my husband dies in the next few years, which is his medical prognosis, I may need support:. I just don't know.

I thank you for taking my views into consideration as part of the Committee's inquiry.

I am willing to provide further information if required.

Yours sincerely

Megan

1 July 2008