

Committee Secretary  
Inquiry into Better Support for Carers  
House of Representatives Standing Committee on Family,  
Community, Housing and Youth  
PO Box 6021  
Parliament House  
CANBERRA ACT 2600

AOC 17/7/08

Submission No. 871  
(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's Inquiry into Better Support for Carers.

I am submitting to the Inquiry because I wish to highlight the very valuable role that carers play in society. There is much joy but also sorrow in this role and I believe that it is undervalued by society as a whole. It is important that carers be given a voice. If, by my sharing my own experience as a working carer, I can help just one person to avoid some of the pit falls I encountered it will be well worthwhile. My own story of caring for my mother began in earnest with the death of my brother nine years ago. My mother's zest for life faded and although she tried valiantly to recover she was never the same. Her deterioration at first was slow but relentless. The last three years the deterioration has been more rapid. In fact, I only asked for help in the last two years. Although services are available to carers trying to access those services is akin to being in an ever increasing maze with illegible signposts so that the carer never really knows where to go or in which direction to take. To add to this mix the carer in this case myself is physically exhausted and emotionally spent. Not a happy combination when trying to understand bureaucratic-speak.

As stated before my role of carer is one of great joy as I have spent much wonderful time with my mother but also much sorrow as I have witnessed her deterioration and my role of daughter has been replaced by that of parent.

I would also like to take this opportunity to thank the DVA and people at Moorfields and Bapcare who helped both my mother and me with services and with kindness. A smile and a kind word mean much to people who are under great stress.

#### **1. The role and contribution of carers in society**

As a carer, I feel that my role is care for all my mother's needs physically, emotionally and mentally. Within society, my caring role is one of service and I contribute to society by relieving society of the burden of hospital care. In my case, my ageing mother's ability to function in society diminished so my role encompassed fulfilling that role for her. To enable her to preserve some dignity in facing her changing world, my role became her carer and champion to buffer her from her inabilities. My role was to make her life easier and attend to her needs and preserve her self respect. My mother deserves respect after a lifetime of service to her own family and society as a whole. She not only deserves respect but has truly earned that respect. In her younger days she left work to care for her dying mother. After she married she not only cared for her mother-in-law who was suffering from dementia but also cared for her father who was bed ridden. When caring for her father she had two very young children. Her contribution to society has been great although unsung. This highlights that carers contribute to society in a quiet manner and are thus unrecognized and are often invisible and are thus undervalued. Carers provide their caree some semblance of dignity and in doing so humanizes sometimes degrading procedures to assist in the comfort of the caree.

Carers also relieve the stretched resources of hospitals, aged care facilities by keeping their caree at home

## **2. The barriers to social and economic participation for carers**

As a carer, I face the following problems when I am working I worry about my mother being home alone during the day. My mother has continence problems which manifests itself in either wetting the bed or up to five trips to the toilet at night. As my mother gets up to the toilet at night so must I as she is a falls risks. This results in sleep deprivation.

Social outings result in doctors and specialists visits or visiting shopping complexes with flat surfaces to facilitate the use of four wheel walking frame or wheelchair. Personally as a carer the social barriers that I face include isolation and loneliness. As my mother could not be left at home alone for any length of time it was impossible for me to go out at night and socialize with friends. There was also the lack of sleep which was impacting on my ability to function. I did not have the energy to plan outings for my mother. When I first began caring for my mother I decided that a social life would be very difficult to maintain so decided to begin a correspondence course through the Open University. This worked well until the last 18 months when sleep deprivation and the worsening of my mother's condition became apparent. Several subjects were deferred so that I have put study on hold for the time being.

As for economic barriers my career has been stalled and my ability to work more hours has been impossible therefore my earning capacity has decreased. I have been unable to participate in extra courses and education to improve my career unless they operate within the shifts that I work. With working fewer hours I have less ability to contribute to superannuation therefore my future is less secure and I may become a greater burden on the Government and society in the future. In fact until my mother only very recent was reclassified as high care and has just gone into permanent care I would have had to leave work to care for her full time. My chances of returning to work after the caring role had ceased would be remote as I am 54yrs old. Although entitled I have never applied for a carer's allowance so have not burdened the Government with my caring role.

## **3. The practical measures required to better support carers**

As a carer, I need help with understanding what is available for carers, how to ask for what is available, how do I find services that are available and to what am I entitled. In other words there needs to be a central point at which services are explained. If for example help is sought from a GP then that GP should have an agency with all the information available then each case could be dealt with on an individual basis. It would also be helpful for a case worker to be assigned to each client seeking help. In my own case I had no one person to whom I could turn for help. As my mother's mobility decreased and mental faculties diminished she required physiotherapy and in home respite. Finally this was achieved but it was insufficient. It may be helpful for more education in the hospital setting for staff to cope with the ageing population. My mother recently was hospitalized after having a fall, however, her being ninety affected her treatment. I discovered it was only the staff from ethnic backgrounds that revered the elderly that any respect was afforded to my mother. The young physiotherapist decided that her mobility was sufficient and that any further rehabilitation was unnecessary. At no time did she consult me but assumed that my mother's mobility had no decreased. This was far from the truth as my mother was attending a physiotherapist on a weekly basis and indeed her mobility had decreased. It may be of value to educate ancillary services in the value humanizing all clients.

When services specific and age appropriate the staff within these services are well educated and afford dignity and importance to their clients.

**4. Strategies to assist carers to access opportunities and choices**

I think the Government can better help carers by making services more user friendly, more available. Navigating some of the government website is a real nightmare so they could improve. When carers initially ask for help the Government could ensure that all services are explained in plain English or in the appropriate language. It is very necessary for these services to be centralized for the ease of distributing those services. In my own case when my mother was hospitalized both social workers and occupational therapists asked me what I needed but until you are in those circumstances you often don't know what you need and you certainly do not know for what you can ask. In fact, I asked a social worker if there were any day-centers to which my mother could attend. I was told that I would need to find that myself. My response was why ask if you are not willing to help I was doing so much I didn't have the energy to do more and I was fobbed off with an insincere offer of help.

It may be a good idea to have lists of services including day-care centre, in-home respite services, cleaning services, physiotherapy, podiatry, occupational therapists and other services. If the ideal of society is to keep the elderly in their own homes for as long as possible then each case should be assigned a case work as soon as help is required. In that way services are prompt relieving carers of undue stress and worry.

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

Anne Marie

*Signature*

ANNE MARIE

*Print your name*

04/07/2008

*Date*

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Contact Telephone Number