

ADC 4/8/08

**Submission No. 1144**

(Inq into better support for carers)

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

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 don't believe you (as a body) have a clear understanding of the needs of carers.

Nor the huge responsibility carers carry.

Many, and I am one of them, have given up full time paid work in exchange for this responsibility without any real compensation

✗ *More information is attached on a separate sheet*

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

As a carer, I feel that my role is...

Reversed Parent. Once upon a time I could go to my mother and talk with her about

most things, even get advice. However, with the onset of dementia, amongst other physical

ailments, she has become so dependent that she no longer has the ability to input into

my life or anyone else's. She has become the child and I have become the parent - but

it is technically not that easy/direct, as I am very aware I am her daughter, and that relationship affects my carers role

✗ *More information is attached on a separate sheet*

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

As a carer, I face the following problems ...

I am house bound, much/most of the time

I am adult input starved, very socially limited

I am over worked, under rested and miss my family and friends and their contact

My financial capacity has become so limited that I could not even afford to reduce my work

load by engaging someone to do some of my chores.

✗ *More information is attached on a separate sheet*

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

As a carer, I need help with ...

My own house work, which has dramatically increased since my mother moved in with us.

Regular overnight assistance – whether in respite or in the home

Just the freedom to just do something for myself at least once a week not restricted by a SET TIME

The freedom and ability to socialize with others who are not carers

*✗ More information is attached on a separate sheet*

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

I think the Government can better help carers by ...

Assessing each case on an individual needs basis, rather than having set criteria within  
which you must fit.

Nursing homes have their place, but do not always meet the need.

*✗ More information is attached on a separate sheet*

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

Mrs Rijntje  
*Print your name*

30/06/08  
*Date*

1. I would like to add something as to why my CARERS ROLE is Reversed Parent, and I trust it will be helpful

The first thing that happens is – confusion sets in.  
Followed by denial, frustration, helplessness, isolation, etc

How could my mother get this? She has always been so hardy, with it, on the go, travelling around Australia on her own in her senior years, taken elderly friends on holidays etc. – denial

You see, to hear someone you love who has always been independent and capable, will now be dependent and possibly incapable, is a huge shock. In my mother's case that was so. She was very angry at first when informed she would no longer be allowed to, nor capable of, living independently. Because she thought living like she was, was ok – double incontinent (which happened over a period of time) happened to all older persons and they all coped with it and said nothing, not eating proper meals (bread was the norm) was good enough after all in the war you were “blessed” to eat anything, sleeping in a bed which had been soiled the day before was ok, having a washing machine full of soiled undergarments and other clothing items was normal, dribbling on the floor on the way to the toilet couldn't be helped and was not really that bad, hiding tablets under and in things instead of taking them and so on – what were they making such a big fuss about. Taking her licence off her was an even bigger issue. How dare they, I have never had an accident nor been fined, etc. (loss of memory is very handy here). This anger was taken out on me the carer – how dare I agree with them (the doctors), I should be on her side. As the carer you become the scapegoat, it is all your fault – frustration plus

How am I going to care for her? How will we manage without my income? How will I be able to manage lifting her, washing her, dressing her, etc? – Helplessness

I never see my friends and my family don't come. Nobody knows how to deal with someone so angry, so incompetent, so demanding etc. So they stay away, because they can't socialize with me anyway as my mother just demands ALL the attention, like a little child – Isolation

Even though I have the carer role, I am still the daughter and that creates a problem all its own thus limiting the “joy” of caring. You see when one cares for a child there is a positive response, but when one cares for someone with dementia, that is not the case.

The same also applies to someone who has been disabled in a motor vehicle accident. I know not all become angry about the “unfair” hand they have been dealt, but when they do and are, and carry that anger they have to let it out somehow and believe me, the carer cops it – I know I have been there too.

2. When a person becomes a carer, that person gives up their life. Others, friends and family, do not feel comfortable in the new setting or with this other person they may or may not know as part of the deal in socializing with the carer.

Therefore the carer becomes a social outcast, due to the responsibility she/he/they have taken on. Their confidence erodes, their charge becomes their world, and their conversation becomes limited due to this restricted world she/he/they now live in.

They are sleep deprived, but cannot just take an afternoon nap as their charge may need constant supervision or demands attention just like my mother.

The pittance received from the government in the form of a pension hardly covers the extra fuel needed to take this person to wherever they need or want to go. The added financial pressure causes friction and tension in other areas of life. In fact the pittance is an insult to the carer and the sacrifice made.

The government greatly underestimates the importance of carers. They, the carers, save the government huge sums of money.

3.
  - (a) Pensions need to be increased
  - (b) Home Help Assistance should not be limited to the “dependents” own home or space, but to the entire home in which they live, as carers rarely get the time to do anything other than care for their charge
  - (c) Assistance with showering should not be restricted to 3 times a week, as most UTI’s are a result of poor hygiene or stale urine and/or fecal matter not properly showered away from the genital area, especially in females.
  - (d) The same relief/respite worker should be sent for the relief or respite in the home for that particular person every time, especially in the case of dementia sufferers as they often have limited cognizance and become very agitated as a result, which them much harder to care for.
  - (e) Just like Palliative Care, all care needs need to be looked at from all facets of care, as each family and each patient is different and cultural obligations have huge implications in the way care is carried out.
  - (f) There should be a full and complete listing of accessible facilities available to carers. All medical facilities should be 100% aware of ALL facilities and assistance available to meet the potential needs of those taking up the responsibility of care. They should not have to go through months of suffering wondering how to handle a situation when councils and hospitals should have this information readily available.

4. I now know there are services available to carers, but it took me 5 months, after becoming a full time carer, out of desperation and at the end of my tether, to locate someone who could direct me to some help and even then the help dribbled in and was never enough or complete.

The government should set up a body/resource unit who makes it their job to collect, connect and document ALL facilities available to/for carers. This body/resource unit should then make ALL medical facilities, whether doctors clinics, hospitals or retirement villages etc aware of whom they are and what they can offer. Then when a patient becomes dependent on a carer, they and their carer can be given the contact number as a first point of contact. They can then do the needs assessment from the carers perspective and direct them to the facility/s best suited to their needs. This will make the facilities more useful and accessible to all those who have/will become carers through no fault of their own. In this way carers can assist the government in a difficult and tedious role which the government does not have the time or ability to address.

The other thing they can do, is employ former carers in this body/resource unit, because they have a full and deep understanding of needs and limitations carers experience.

Going back into the work force is another aspect the government needs to address. When a carer has been in the position of carer, and out of the work force for a while, as in my case, getting a job is harder due to the eroded confidence, lack of up to date skills and being out of touch with the present trends within the work force. The government needs to, as a priority, assist such people to upgrade their skills to enable them to re-enter the work force, so that they can become fulfilled citizens one again.