

# Submission No. 611

(Inq into better support for carers)

A. O. C. 8/7/08

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Committee Secretary  
Standing Committee on Family, Community, Housing and Youth  
PO Box 6021  
House of Representatives  
Parliament House  
CANBERRA ACT 2600

Dear Secretary

We 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 on behalf of our support group for daughters who are carers.

These are the thoughts members of our group wish to express in regard to the very complex role as carers. This relates to 2 special groups – aged carers and daughters who provide multiple support roles. The role of carers are very undervalued with little understanding of changes in lifestyle required to meet needs of person being cared for. Problems associated with full time caring are significant.

- Difficulty accessing community based supports at time of diagnosis. This is particularly relevant in country areas where person may be on waiting list for several months. This increases the pressure on carers, often with their own ageing or health issues unable to be considered.
- Anxiety about what help would be available to the person if carer became unwell/unable to provide level of care required.
- The need for extensive family support for carer as well as person being cared for due to the length of time people are expected to manage at home.
- Pressure to "stay at home as long as possible" – leads to feelings of guilt when not able to continue meeting increased care needs. Often this is for a number of years even for elderly spouse carers, they require family support.
- Carer respite (Day) is only available in the middle of the day on week days. This results in carers becoming socially isolated from any regular group or evening activities which are necessary for their emotional and psychological wellbeing. Once caring role stops due to death, carer has no social contacts left in most cases.

**Solution:** Availability of flexible day respite – evenings/weekends to reduce carer isolation.

- Difficulty in understanding of diagnoses and it's implications impacts on ability to make clear decisions at time of high stress. Carers are expected to know what to do.
- Anxiety about "will it happen to me" in cases of dementia "will I be remembered " and not seen as another person when trying to assist.

## **Financial:**

- High financial cost of meeting needs to attend appointments, petrol, often long distances to major centres; 300 – 400km for Specialists.
- Cost also includes accommodation during any carer hospitalisation for acute care. Can be prohibitive in enabling carer to be with patient.
- Geographical isolation from person requiring care due to cost again causes guilt and often important decisions need to be made regarding future care needs while in acute care.

- Being required to arrange transport back home at time of discharge – often the person's condition has not stabilised and public transport not an option causes both financial and physical difficulty. Country people are required to find their own way home from city admissions.
- Carer needs to be present if Aged Care Assessment is being conducted in acute care setting due to future care planning.
- High demand for any accommodation for country visitors, often expensive, no subsidies if not related to Palliative Care. This increases both financial burden and sense of isolation for carers, compromising their own health and ability to manage.
- Need to re-present at A&E – changes in health not always seen as acute – sent home then carers unable to manage, staff need to listen to carers about changes in condition.

**Residential Care Specific Care Needs:**

- There is a need to acknowledge carer role continues once person is admitted to Residential Care. There is not any government assistance financially for this – may be more expensive than caring at home.
- Guilt about need for residential care of parents or spouse, very emotionally draining loss of pension increase the financial burden on remaining carer at home.
- Increase residential care staff understanding of extensive carer knowledge about new residents care need. Often treated as if they have little or no understanding of care needs, demoralising and reduces sense of trust by carers. This also increases isolation and grief. Need to work together and provide some initial support to carers.
- Need for staff to recognise person also has significant other people involved in their lives “not only a care need but a person”.
- Staff can be overprotective of resident's privacy to the exclusion of carers – can be seen as negative and isolating family carers.
- May need register of unwanted visitors if this is an issue causing anxiety for carers – loss of any input to care needs – especially difficulties within the family.
- Staff education on management of dementia often seen as inadequate to manage, difficult situation in early stages.
- Need for counselling for families at time of marked changes in parents need for “children” to reverse roles in decision making – maintain dignity of parents. Particularly difficult if good cognition with high physical needs.

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

Regards

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