

ADC 17/7/08

Submission No. 891  
(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 Committee's Inquiry into Better Support for Carers.

I am submitting to the Inquiry because I have cared for my aged father over the past ten years through stages of dementia ( he now has advanced dementia) and have experienced in very real terms life transforming changes that have overwhelmed me emotionally, physically and financially.

The sharing of my personal experiences, I hope, will add strength to those of other carers in brining to bear on government policies and practices to reflect recognition of the pressures carers are subject to and act to relieve carers of their difficulties. I hope changes will result so that hopefully I can enjoy in some relief but if not for the increasing number of future dementia sufferers and their family carers.

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

***A glimpse of what I do as a carer might give an idea of the contribution I make to the community like other carers : I am 60 years old, and have cared for my ageing father for the past 10 years on my own with some help from family members. For the past 4 years he has needed 24/7 care with full physical assistance required. I have the help of a carer for 16 hours per week provided under the Extended Agecare At Home (EACH) program. I do the remainder of day hours for 5 days and night hours for 7 nights to ensure no bed sores occur. I do a total of no less than 150 hours a week of caring on top of 10 hours a week of part-time paid work. I buy 8 hours of care for my father when I look after my two grandchildren to enable their mother to be in paid part-time work.***

As a carer, I feel my role in personal terms fulfils my parent's wish to be with his family and to die at home. In broader and more tangible terms, I feel believe carers deliver savings and relieve the community and the government the burden to care for their relatives. I have been told by friends and acquaintances that I am 'a saint', that 'the government should give you a medal for saving the taxpayers money'. I am vaguely aware I save the community half the costs incurred if I put my parent in a nursing home. But that is not all. More importantly I believe as part of my 'ethnic' acculturation that how we care for our elderly and others who are dependent on us reflects us as a society. In that sense the contribution of carers is priceless.

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

As a carer, I have felt isolated. I have faced and am facing the following problems that limit me in full economic and social participation :

- **Employment:** I was a manager when I decided to take up the caring for my father when he was diagnosed with dementia. I asked for an 0.8 appointment but was turned down by my employer (a government funded body), the reason being I could not be a 'part-time manager'. I had to downshift and took up a part-time non-managerial position, offered by another similar organization, with a reduction of 60% income: that led to an upheaval to my retirement plan. The flexibility given to me was provided by a sympathetic manager in the new job. I had to retire prematurely due to poor health last year although financially I could not afford nor want to do so.
- **Ill-health, sheer exhaustion and financial difficulties;** These factors limit my ability to keep up with social contacts. As a carer, I feel I belong to an army of faceless, invisible 'martyr-like' personas not fully given public acknowledgement and fully understood by family members who are not directly engaged in caring and social circle, let alone the wider community. One is often too exhausted and financially inadequate to keep up with the same friends.
- **Disempowerment.** Moving into the role of carer, I discovered has been a journey of disempowerment. You have to ferret for information, negotiate a maze to access information, service provisions; you are eyed suspiciously for taking advantage of services and you have to negotiate for respite etc, etc. I often feel like a beggar. These factors contribute to depression suffered by carers.

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

- **Financial help.** 'Help' is not a good word. If I worked the hours caring for my father in aged care facilities I would be paid. I would be paid heaps for the 150 hours I work. I propose a wage for carers for family members. I don't get paid and I dip into my retirement funds to buy care for him when I things get overwhelming. I am grateful for the carer allowance but that often goes into medical expenses. 10 years ago, I was looking forward to a self funded retirement plan, now, I'd be lucky if I could retire with out some form of taxpayer assistance.
- **Provide financial advice to ageing carers.**
  - Set up a financial advisory service to carers to help them plan a provision for themselves as they age themselves. Government can act as interest free lenders for payment of mortgages and caring expenses.
  - Remunerate carers appropriately. Certify carers with vocational qualifications and give them a wage commensurate to the work they do in caring.
- **Prioritized health care arrangements.**  
I waited a total of 3 years from diagnosis to surgery to remove pain while continuing the carer role. I have not been able to fix my two knees injured in caring over the last 4 years. Carers are known to have least concern for their own healthcare and the inadequacies of the healthcare system have proved unhelpful.
- **Review the aged care packages.** I have felt frustration and penalized in the arrangements of the packages set out by the government. The EACH package awarded to my father provides only 16 hours/week of care, I do 152

hours and the rest of the funds go into case management by a service provider. Case management in my case provides a monthly visit, a supply of continence pads. I sought for the carer myself to be put on their payroll. A recent challenge to the provisions provided an alternative that will help carers to a great extent. The package was reconfigured to allow for an extra 16 hours of care by reducing the overbalanced funding to service providers for case management. I have wanted more say in case management to provide a more balanced usage of the funds under the package. It can yield at least 32 hours of direct care for my father if case management took 10% of funds provided without more taxpayer money. I urge the Government to act on this immediately for EACH recipients. A full 16 additional hours will give me the respite I want physically and financially because I don't have to buy extra help to give me rest. It also gives me back the EMPOWERMENT: I have felt reduced: from being a manager before managing a multimillion dollar budget to being 'told' I could not manage a care package for my father!!!! I sometimes do feel like a beggar, asking for a few hours of respite and continence pads for my father!

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

- **Caring revolution.** I commend the Prime Minister on his vision of the future of education in our country. I would like to add further my vision of a more caring Australian society built on a the younger generation gaining hands-on-experience with caring. Build it into the curriculum. I have met Scandinavian young people who have invariably had experience working in childcare or aged facilities as part of their education. Apart from building a more caring and compassionate society It makes economic sense: I was unprepared for caring f or my parent in old age in this way; with the growing incidence of dementia Australia needs more families to care for their own or the health system collapses.
- **Raise the profile of caring**  
What about renaming the Ministry of Family, Community, Housing and Youth to **the Ministry of Family, Caring, Community, Housing and Youth**. The role of caring has been 'hidden' for so long that it makes it impossible for the community to regard caring a significant and acknowledged role as compared to abandoning your elderly and disabled in institutionalized care.
- **Set up a one -stop-shop and Register of carers.**  
Managed by a one-stop-shop agency to provide first time carers
  - access to information and how to work through the system ( In the first place, why should and how can one expect carers have to work through the fragmented system?)
  - a case manager to help people from a 'life with your own life' into a 'life without your own' as they take on a carer role
- **Overhaul the financial provisions granted to carer recipients and carers.**  
I believe the current fragmented system is cost heavy and inefficient causing more administration costs which can go into direct care and support for care recipients and their carers. It takes courage of any government to do this but it has to be done before the burden exacerbates. I see myself as an example. I

have saved and worked hard to ensure I fund my own retirement but caring has debilitated me to the point I may end up dependent on the community which is disempowering to me. It could have been avoided as I have reflected.

- **Review the government aged care packages.**  
See above

Thank you for taking my views into consideration as part of the Inquiry. I look forward to reviewing any recommendation you make to improve life for carers in Australia.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Mo-Lee', with a horizontal line underneath.

Mo-Lee

4 July 2008