

Submission No. 737

(Inq into better support for carers)

A.O.C. 14/1/08

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

Dear Secretary,

We wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing & Youth's Inquiry into "Better Support for Carers".

We - Judy I (aged 55yrs) & spouse Deane (aged 54yrs) – are fulltime Carers for Judy's Parents.

Judy's mother (aged 83yrs) was diagnosed with Alzheimer's disease approx 6 years ago.

Judy's father (aged 89 yrs) is a DVA TPI ex-POW (Japan) and amongst many ailments, suffers – respiratory failure (on oxygen 24hrs), cardiac arrhythmia (controlled via a pacemaker), arthritis, glaucoma & total blindness in the right eye, macular degeneration in the left eye (approx 20% vision), profound deafness, kidney ailments along with other cardiac conditions.

From 2003 to 2005 Judy spent each weekday travelling to their home of some 50 years, to provide Care for them both. In 2004, it was decided that this could not continue and – along with Judy's 2 siblings – there were 2 solutions available.

A Nursing Home (which no party wanted), or "live-in" full time Caring. Despite the protestations of Judy's siblings, we owned a block of land adjacent to our home. We built a "specific/purpose" home to enable us to both live with her Mother & Father – and continue to provide "in home care".

This home took 12mths construction and all 4 of us have lived here for approaching 3 years.

Without having opted for this course of action as Carers, we have no doubt that her Mother would no longer be alive.

She simply would not have survived the "standard treatment" supplied in a Nursing Home.

Without having opted for this course of action as Carers, we have no doubt that her Father would quite possibly no longer be alive, or at least be without his wife of 61 years.

Our contribution to both Australian Society and Judy's Mother and Father have reduced the call on Federal Government funds for places in 2 Nursing Homes (as each party would have been separated – High Care & Low Care initially. Both now High Care)

We receive no assistance from Judy's siblings, although the provision – after some time – of EACH packages – has assisted somewhat. However, we had no idea how

or who to approach or that such programs existed. Fortunately we found out before Judy came close to complete physical and mental failure.

We are unable to participate in a normal social life as we cannot leave them alone at any time. We are "on call" 24hrs a day, 365 days a year.

We have not had a holiday for 4 years (around the time the house contract was signed). In the almost 3 years of "in home full time Care", we have had 2 nights respite, and 2 nights out on a Saturday -- and these have only been in the last month.

We are like "ships that pass in the night".....and the only time we have to even talk is at bedtime at the end of the day.....but we are both usually exhausted.

In terms of Employment, Judy has been a homemaker since our children were born (1977 & 1979). I have worked for Telstra for almost 15 years. For almost 2 years, I worked 3 days from home & 2 days in the CBD. This enabled me to provide assistance to Judy -- with general Caring, Doctor's Appointments etc for her Father.

Regretfully, this combination of work/caring balance became too much for me (Deane) & in December 2006, I was diagnosed with severe depression. I have been on "Sick Leave Without Pay" since, and may do so for a further 6 to 12mths of therapy.

Judy has been taking anti-depressant medication for some years now (when she almost collapsed -- as mentioned earlier).

In the meantime, I am in receipt -- as is Judy -- of a part-Carer's Payment via Centrelink . In addition, I receive some income support from my "Super Income Protection". Judy receives the Carer Allowance for both her Mother & Father.

I suspect and have a reasonable expectation that I will be "Medically Retired/Terminated" from Telstra. This provides no benefit (other than Annual & LSL) but places me in a "non-working" position, should the Caring Duties cease.

Despite what any Government, private or public authority says, at the respective ages of 54 & 55 yrs -- we will find it near impossible to re-enter the workforce. Age discrimination is alive and well and in my case (Deane), I would never expect I could secure a job such as I have (by tenterhooks) at this stage with Telstra -- both financially and use of my knowledge.

We both have absolute uncertainty of our future -- in employment and Caring.

Bearing in mind the ages of the parties being cared for and their conditions -- we could be caring for 2 weeks or 10 years -- we have no way of predicting the future.

The Future worries us both as we know not what will happen on the personal/health/financial plane, coupled with employment uncertainty as outlined above.

What we can say is the we :

- Have 15 hour physically & mentally demanding days 356 days a year -- 15 hrs plus broken sleep
- No opportunity for proper respite or a "holiday" at any time to "recharge" and being under constant, unrelenting stress.

- The inability to access the "Superannuation Co-contribution" program as our "work" is not deemed "payment for work"
- Constant physical and mental demands & the need to "survive" ourselves with medical conditions that many in the "paid workforce" would never do.
- No idea of how to plan or what to look forward to in our "retirement" years – which are 10 years away.
- Receiving no assistance from Judy's siblings – who's sole focus is on what they may inherit financially when their parents pass away.
- Having had to enter a complex arrangement drawn up by a Solicitor, with a "contingent debt" to the Estate of the last survivor, should we not continue providing in home care for 5yrs – to quell the point immediately above.

Both parties require constant medical attention from Doctors from varying "specialities".

Our lives are anything but "normal" by anyone's standards.

Our needs and help relate predominantly to the matters of :

- Financial uncertainty
- Employment uncertainty – especially due to our ages
- The physical & mental stress 365 days a year, 24 hrs a day
- The lack of "proper" respite – as in more than 2 days off in almost 3 years
- Inability to take part in and plan any Superannuation for our future

What would help us and recommendations we make to your Committee are :

- If the Super Co-contribution scheme is to continue to "lock us out", the continuation of the "Carers Bonus Payments" as part of the Budget process. This is what they are used for – payments to our modest Super Funds
- Improved and easily accessible "respite" by other care Workers in our home, to enable us to "have a break"
- Should the "bonus payments" be discontinued, as they were prematurely advised, only to have the decision reversed by the Prime Minister in the lead up to the 2007 Budget – there must be some other form of "compensation" which would alleviate the uncertain futures we have.
- We would propose that some form of "advanced Age Pension entitlement" be granted to Carers, say over 55yrs, who have been Caring & in receipt of the Carer Payment for 5 years. For instance, if a Carer has provided 5yrs of Caring, and the person they care for passes away, and the Carer is over 55, they become immediately eligible for the means tested Aged Pension – which of course is predominantly available only upon reaching age 65.
- If the above suggestion is "too radical" and deemed unaffordable, then the reintroduction of the "Mature Age Allowance". This was created by the previous Labour Government – "grandfathered" and discontinued by the subsequent Coalition Government for "new" applicants. This applied to people over the age of 60yrs who were seen as "unemployable". Using the criteria in the point immediately above, a grant of the "Mature Age Allowance" to Carers over 55yrs, who had been continuously in receipt of the Carer Payment for 5 years, would provide some certainty and ability to plan for the future.

There are numerous Benefits and Pensions paid via transfer payments to people in all manner of situations in life – unemployed, sick, elderly, veterans and so on.

Without placing any negative spin on those payments, Carers are in a “group of their own”.....quite often with no connection to these other groups.

They “volunteer” to undertake a task which in their absence, would have to be undertaken by the State in the form of Nursing Home places – which require large capital expenditure – and ongoing costs.

Carers never know at which point of their life, they will be required to “volunteer” for this “duty”. Equally, they never know how long or short that role may be.

The rest of the world doesn't put their lives on “hold” – nor do their employers, or relatives – for whatever period it may involve.

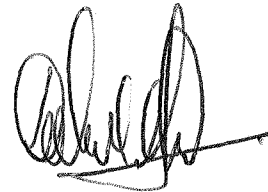
Carers suffer more widely – both physically and mentally with health problems which further exacerbate the time Caring and the “whatever comes after” Caring.

Carers are a “special” group of individuals that undertake some of the most difficult, hardest “work” there is. And they receive very little thanks after the event – from relatives, employers, Governments, or society at large.

Thank you for taking our 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,

Judy

A handwritten signature in black ink, appearing to be 'Deane', written in a cursive style with a long horizontal stroke at the end.

Deane

30 June 2008