

NB: My phone number is

a silent one.

31 July 2008

Submission No. 1274
(Inq into better support for carers)

Committee Secretary
Standing Committee on Family,
Community, Housing and Youth
AOC 5/9/08
P.O. Box 6021
House of Representatives
Parliament House
CANBERRA
ACT 2600

Dear Secretary,

I want to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

Thank you very much for this opportunity to share my views and experience.

I am a single woman with no dependants who has been the primary carer for my mother for 1 month short of 13 years.

Why have I given you this detail?
I will answer you as I address the
four key terms of reference for the
Inquiry.

g) The role and contribution of carers
in society and how this should be
recognised:

- You will find as you read the
other submissions the the word
"carer" can mean many things.
Even if a person is a "primary
carer" their major function/s
can differ and therefore their
contribution to society and the
responses to the other three key
terms of reference can and
will differ.

eg not just the person being
cared for eg baby,
young child, accident
victim, spouse, parent,
frail aged

but whether they are caring
"in home" for the person/s
or whether the cared for person
is located in a hospice,
nursing home, sheltered home or

group house for people with intellectual, brain or mental illness.

The amount or kind of care given at home eg the carer does the vast majority and it is one-on-one hands on or there are professionals who come to the house daily and the carer supports them.

Therefore there is a need to

- a) understand the different kinds of caring / carers
- b) maybe giving them a specific name, title or status to differentiate between them.
- c) obviously the contribution of a carer in the different categories would differ.

Presently I believe there is little understanding in the mid years to younger generation of what a "carer" is or does. This is a problem because these are the people who pay taxes now or will do in the future and will have a say in how they are distributed. Also they are the people who will / may become involved in caring in the future.

When I left work to look after mum I had no idea of the role / word "carer". It was only when I took her to the hospital for a medical appointment that the receptionist told me - in answer to my comment that I had no occupation as I had stopped work to look after her - then those words "Oh no - you have a job you're a carer". That had

...a profound effect on me. That was
...the first time that I was aware
that was what I now was and what
...I was now doing was called.

...However, my boss - who was about
...10 years younger than me told me I
...was retiring - as if I was now on
...holiday, because I was stopping
...work to look after mum.

The doctors in the medical profession
and even nurses at the medical
centre did not tell me much if
anything about things to aid/help
carers.

"The Single/sole parent role is more
widely understood in society, while
the "carer" role is not. This is also
reflected in my answers to the
other key terms.

Referring to our contribution
to society, well, the financial
benefit we provide is enormous.

I became a 24 hour 7 day a
week, nurse, housekeeper, adminis-
trator, occupational therapist,
entertainer, physiotherapist, cook,
social secretary to name some
of the many things I did.

Even nurses in "intensive care"
ward in a hospital have 7 hours
off work a day. They get
paid for shift work, night work
and public holidays and week-
ends. I am not saying I
should be paid as they and
the other occupations listed above

as far as allowances for overtime and night rates, etc. But we are undervalued, rated and not understood.

Government is freed up to pay out money for other things because "carers" and those "cared for", plus sometimes family provide free or pay for the caring costs.

I also believe it is important that society is a caring one, eg, that people whatever their condition of health/need are appreciated and valued, and lifting up the role of caring for more than children as a worthwhile thing to do is very important.

Other suggestions follow later in this submission.

b) The barriers[†] to social and economic participation for carers, with a particular focus on helping carers to find/or retain employment:

*These are many

a) social = isolation both in being housebound most of the time and also inability to socialize in the usual manner.

with a lack of understanding of the responsibilities and day to day activities/requirements of caring, people can avoid involving a carer in their social life. It's like I'm invisible.

I was[‡] part of a group that

met in my house regularly.

Over a 12 month period I was only asked once how my week had been. All the others were asked by the leader almost every time we met.

I have rarely been invited to do anything whatsoever by anyone * since I came to Canberra with mum to be nearer family (*outside my family)

One person did invite me to go for a car ride a few times but, either I wasn't well, didn't have clean clothes ready to wear, or needed my shoes repaired, didn't have anyone to be with mum, or didn't have the money to spend on a coffee or entry ticket. After a few "sorry 'no" the invites stopped.

• Also my time wasn't free when their's was. I almost never had free time

b) Economic participation: working 24 hrs x 7 days a week as a carer with no suitable respite when the cared for person was going through a crisis situation and/or recovery from such, either of which could involve hospitalisation, surgery or medical appointments where I needed to be present plus carrying out the rehab programme not only precluded employment but there could be conflict of interests and there was only a limited amount of leave available and I couldn't make time up. This meant while I was involved with the caring of

Mum, I became exhausted, depleted, entered burnout twice and had to deal with my own health issues, including, osteoporosis diagnosis and a bout of malaria type symptoms that took me about 4 months to recover from. All with almost nil respite.

As far as retaining employment - I did continue ^{full time} in my teaching position for about 18⁺ months after Mum had her first and severe stroke. Mum was either in hospital more than once for several weeks at a time and then went by ambulance with a nurse to hospital day care rehabilitation 2 days a week. She rested mostly in bed the other days and I was home at the weekend. However for 12 months I only had weekend and public or holiday leave. I had used all my other leave up.

Another barrier apart from the role of health is the fact that as time goes by our health becomes affected and our skill sharpness or up to date knowledge reduces and new technology passes us by. We therefore need to look for alternative employment as we may no longer be able to do our previous work.

e) The practical measures required to better support carers, including key priorities for action:

I believe the following would aid
carers in the role
Financial:

○ Permanent granting of the "carer
bonus". This for me was not
a luxury but enabled me to pay
the huge winter heating bill and
buy a pair of shoes to replace my
badly worn pair. This bonus is
wonderful because it can be kept
outside our regular Centerlink
budget.

○ Carers struggle financially **

○ Allowances/discounts on utilities*
to be extended to include carers
(a criteria would need to be

devised eg maybe just for
primary no working/employed
carers) see Centerlink

payments to Seniors. This
would apply before we become
Seniors as it is for carers
who fit whatever criteria is
established eg low income,
primary carer etc.

○ Also if after caring we are on
a low-income (level to be
established) and/or not full-time
working but ^{maybe} on a centerlink
payment these allowances/
discounts continue.

○ OR These discounts/allowances
continue for a specific time
after caring ceases eg 1 yr.
Centerlink concession card
continues for carers on a
low income or centerlink
payment after they stop
caring and are over 50.

- The notion of Family to be extended to include a single carer caring for a parent in a primary live in carer role. This would allow for them to be able to claim the discounts on electricity, gas, land rates which are available to married couples and parents with school-age children.

My mother and I could not obtain these discounts as I was not a dependent child yet we were living in a family environment, sharing living costs etc and on a low income. It would help spread this money further and not cost the Government.

There is a need for more respite options. As the number of carers requiring respite increases there is a large number of people seeking assistance from a limited fund of money. There needs to be a more creative, out of the box approach to meet carers needs while allowing the funding available to be spread further = eg small groups of cared for persons looked after in a carer's home. Eg the carer would be either paid for the service or acquires credits towards respite for

themselves. I believe
funding to Carers organisations
should be increased

and b) used in a way that different
carers across organizations
and associations are brought
together so there doesn't
need to be a duplication
of funding/services

I beg ms carers meet with
carers in a similar
non ms carer role in
small groups for mutual
support and education.

* * * As a carer my savings are
down to about \$45. I cannot
afford to get broken teeth fixed
unless I increase my mortgage
then pay fees to do so plus
more interest. I could ask for
up to \$500 from centerlink in
advance but I cannot afford
to pay \$50 a pay or
month back as I need all
of it each month.

I have no superannuation
and at present my health
is recovering from a long term
caring role so I cannot
work.

Therefore any assistance
the government can give
is appreciated as I have
and others too are
not saving money for them.

- Funding for counselling to be increased. I have used this service and it is most essential to help keep carers out of using the health system.

- Funding to be continued / expanded for educating carers in specific's in the caring role eg CIT skills for carers.
 - This funding for education and training to be extended to include not only primary carers but also secondary carers.

my sister worked full time but also spent time with mum and I. It would help her not to get injured etc if she could have training also in caring skills especially when she and mum were alone eg how to lift mum without breaking mum's bones or hurting/injuring my sister. At the moment I don't think there is much ^{training} for her.

- also so carers could have free Red Cross First Aid courses etc.

- Also provision of the recognis of secondary carers to allow for training and education.

- Funding access to carers of cared for persons for larger

e) strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

I think the Government can better help Carers by increasing the range of opportunities in choices of return to work programmes. Currently in Canberra there are some opportunities for women who want to return to work having been out of the work force for an extended period of time. However the key word is "mums". When I enquired of what about a single female caring for her mum, I was told "no one had ever asked them for a carer to join". They recommended I apply but my application would go through the usual channels and may have to go to the Director/CEO who may need to ask the Minister for approval. As I am in transition from almost 13 yrs caring and have experienced a lot of isolation I need some programmes with women who I am like me we encourage each other. I enclose some examples of what I am referring to. It would seem that at present carers returning to the workforce after

an extended period of time are either rare or yet to be recognized as a specific group of women (in particular) needing support. Except for one or two Government funded programmes, one of through DEWAR I don't think there is anything specific for male carers returning to the workforce after an extended period of caring.

• Also the Jet programme run through Centerlink is a very useful programme for carers as it allows education to refresh or upskill or even to try something while still caring but without the requirement of working when the course is finished. This is one way that carers who unlike me are able to take the time to see where future work opportunities lie. I recommend this programme or something similar be maintained/provided for carers.

→ Also for carers to access the same range of opportunities & choices the Jet programme or similar is essential as well as the acknowledgement of secondary carers to share or swap on a short term/long term basis with the primary carer.

There needs to be a greater
a) understanding in education and workforce about the needs of a carer worker = eg society already knows the special requirements of working

mums and dads - now it needs to become acquainted with Carers special needs - this includes Center-link and Job Network Providers and all Job Recruiting / Employment Agencies. From my personal experience it is not usual to find the young people who often attended to me having an or even any understanding of my "special" situation / requirements as a carer. They need to be educated so they can do a better job of aiding us. Also I need retaining with mature people not first job seekers as I have slowed down. I mentioned earlier the idea of a broader definition of family for parent or adult child / sibling & sibling when utility Companies including Land Tax & other local Govt bodies so Carers who are usually on a low income or also often the person they care for can access additional financial help.

The Bereavement payment to be continued for Carers. I was left with big electricity and telephone bills and my income had been slashed by more than half.

The carer allowance as well as the carer payment both continue to be paid for at least three months after a bereavement of the cared for person or the cared for person enters a hostel / nursing home. The at home

bills which will still arrive have to be paid as well as nursing home/hostel etc expenses. Usually the carer would not be well enough to start work immediately and earn some money. I certainly haven't been able to

Regarding capacity for choices within my caring role - I have already mentioned the ability of greater involvement/knowledge flexibility of 1 or more secondary carers and a way to include them in the education/training/caring role even maybe swapping for periods of time as the primary carer and a way that Centerlink could allow for this either for only primary carer to have a temporary cessation of payment or allow for transfer to a) another primary carer eg the currently recognized secondary carer or another person to become "primary" carer without the 1st primary carer losing a ^{centerlink} say study grant or training grant or do a set course full time and centerlink allow another person temporarily take over the "primary caring role".

The effect of caring long term on me has meant my health has been compromised, new technology has passed me by eg internet, I have had to slow down & become less sharp of mind (temporarily I hope)

and it seems like I have been away from the world. I have gained a wonderful relationship with my mother and learnt to live on almost next to nothing — however my health and well being now need working on and I need time and help with finance and resources to become a productive member of society again.

- At the moment my options are few: -
 - work - my health doesn't allow just yet
 - newstart on incapacity (which is for a limited time)

I have been told I need to care for myself. However having given out so much of my - self / time / resources there is not much left at the moment.

When Mum and I were living in New Zealand the N. Z Government makes provision for people like me, in my special situation.

The Domestic Purposes Benefit Woman Alone allows for single ie (alone) who is 50 years or over and has cared for an incapacitated relative for at least 5 years can be paid \$12191 a week until they reach age pension age without any obligation. I would meet with a case manager who would encourage me to come out of isolation, maybe do some volunteer work or even pay for some training or even university study and if I want

to and am able, they will assist me to do a resume and find a job. What is most helpful for me and carers like me is that provision of the woman Alone payment means I can focus first on recovering my health not compromise my health because Newstart only allows a short period and I have experienced at times anxiety and great stress trying to make a faster transition than is healthy for me and so both myself, family who look on and see me struggle at times, society and the Government are all paying the price.

I have been unable to ascertain how many single woman carers 50 yrs or over there are in Australia, but I have met almost no one in Canberra where I live. If my category of carer is small then the cost to government may be smaller to provide me & other carers the woman Alone Payment plus the Aged Pension extras eg blue concession card, utilities payment etc than for me to be a drain on the health system if I were to go in & out of incapacity & be unproductive, because I am expected to spring back to my former health too quickly. When I

recover I can do volunteer or paid work or a combination of both.

- The transition into caring has been somewhat easier than out of primary caring. I was younger healthier, had more money and the person I cared for although severely unwell to start with has had periods of time when she could contribute to family life and my caring role was not in crisis mode.

However early training in my mother's special needs and requirements was lacking. I learnt some things the hard way and could have functioned better healthier and more effectively.

A note from a person/carer who is already in the role I am commencing, both to encourage and advise me on the personal side of aspects of caring would help enormously. Carers Act have tried personal mentoring, however not many people took up the offer. Therefore I am recommending a personal note.

An invitation/preferably personally to a carers meeting/support group would also help. Knowing that "Carers" are there for advice is great. As for transiting out = this is most challenging for me - each person will be different - many will be younger or handing over to an institution, but

it seems like I have been in a tunnel and the transition is taking a long time. My life had become mostly in the home, I know few people here and my health and finances have meant that I am having to take things slowly.

Financially things have been very tight. I am grateful the Governments of New Zealand and Australia recognize and give financial help to carers. However at the moment only New Zealand has the "woman Alone payment for Single woman over 50 years. Something like this would provide me with a stepping stone to a smoother healthier transition so I don't end up in the deep end, rather than progressing steadily to training / study, volunteer or paid work.

I believe there is a great need for stepping stone programmes for carers leaving a long time primary caring role. Having an ongoing concession card maybe means tested for low income ex carers would also assist greatly. Counselling has also been a great help as I have stopped caring full time. Coming out of Tona

and away from social and educational opportunities with a life focused on caring it is not easy to think or plan for the future. One day at a time - even learning how to go to sleep normally rather than collapsing into bed exhausted, giving myself permission to window shop and stop running, yes literally running from one level of the shopping mall from the Bank to woolworth's because time out had been so short needed to be re thought & transition and the future need not only a new mindset but time.

Thanks 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 faithfully