

House of Representatives Standing Committee on Family,  
Community Housing and Youth.  
fchy.reps@aph.gov.au

Submission: Inquiry into better support for Carers.

Background.

In the 70's when our two daughters were in primary school, we chose to adopt a 5 year old boy

Later, my mother came into my care. I was a full time carer over 17 years. Our son is now independent, and my mother deceased. I have also for many years supported my brother and his wife. They have cared for 20 years for her blind, frail 101 year old mother with memory loss. I help them by providing respite, as all 3 stay with me for 5 days a month. I also assist others in my community.

While I was in my main caring role, to prepare myself for my post caring role, I initially went back to the local school and completed HSC over 4 years. I then completed a correspondence degree in Health Sciences, a conversion course for hospital trained nurses. I majored in Mental Health and Drug/Alcohol. Later I completed a Grad Dip in Women's Health from Melbourne Uni. I could get respite ½ a day a week from family members. I wrote a great essay on Negative Carer Health Behaviours while I concurrently did my back, then broke my leg and quite inappropriately kept on with the caring role for several more years. (!!)

By the time Mum died I was highly qualified. I was a physical and emotional wreck. There was no way I wanted to care for anyone. I needed to mend. I needed time to mend.

I was a foundation member of Carers Vic, and attended the first International Conference on Family care in London in 1998 where I made a short (3 min) speech on Carer Health Behaviors. I shared my own inappropriate behaviour and challenged them to care for themselves. An informal general attitude I picked up at this conference was that those countries who had been British colonies (Australia, Canada, South Africa etc) seemed to have the mind set that "Women should do this caring work" On the other hand I noticed that the Scandinavian countries seemed to be saying "This person with a disability is to be cared for with dignity".

I am now an aged pensioner, with a chronic back injury directly related to the caring (and previous nursing) role. I am able to make this submission because I am no longer a full time carer 7 day a week, 24 hour a day, and have set aside my TAFE study time to write this submission (10 hours so far). I am now completing year 10 of a 6 year TAFE course- Correspondence. Diploma of Art in Tapestry Weaving. This art related course has been part of the healing from the intensive caring role. I have for many years attended Hydrotherapy, and I bushwalk, and am involved as a volunteer in community activities.

As I write, many Australian Carers, are too busy, too tired, or covered in urine, faeces and vomit, laundry powder, detergent and disinfectant... and do not have time or energy to put together two thoughts, let alone two words, to inform you.

***This is why our peak Carer and Disability bodies need to be listened to carefully.***

I am happy to assist further should you wish.  
Yours faithfully,

26/5/08

**The Role and contribution of Carers in society and how this should be recognized**

\*Carer of person with disability where the person with disabilities has been born, fostered, adopted, or brought into the family; where there may be several different carers; where the carer/s may live at different address to the dependant person; where the carer may have care responsibilities for several people who may have different disabilities and possibly competing or conflicting needs at the same time.

**The Carer juggles many, sometimes conflicting, roles at the same time.**

<p><b>Roles in relation to the dependant person</b></p>	<p><b>Home worker, nurse</b> providing and monitoring activities of daily living food, shelter, hygiene, etc <b>detective, researcher, advocate, protector</b> in working out what is wrong, who to see and how to assist dependant person to get to full potential <b>secretary, transport agent,</b> to fill in forms, get dependant person to and from anywhere he/she needs to go, <b>rehabilitator, legal or financial guardian ...etc</b></p>
<p><b>Other roles in relation to partner, other children ,siblings ,animals, or community</b></p>	<p>May be lover, carer, breadwinner, home maker, financial advisor, counselor, peace maker, chief cook and bottle washer, support person, educator, nurturer, mental and physical health advocate.. Finder of lost library books, homework consultant, volunteers for school or community activities. Animal wrangler, Gardner, neighbor, relative to other family members, translator, political advocate...</p>
<p><b>Roles in relation to self</b></p>	<p>Carer of self in relation to mental and physical health, exercise, education, happiness, personal integrity etc ... Child as carer of parent or sibling or other family member</p>
<p><b>Other Roles ( the darker side)</b></p>	<p>The Carer may be the <b>victim</b> who is being, or has been abused by the dependant person or other family members  The Carer may be <b>the abuser</b> of the dependant person.  The Carer may at times <b>loathe</b> their role yet may feel powerless to do anything about the situation they may be an <b>unwilling carer</b>.  They may be the one who <b>inappropriately prevents</b> others from access to the dependant person or their finances.  Carers often show <b>addictive Behaviours</b> in relation to their caring role. ( unable to give it up, or accept help).</p>
<p><b>Role in relation to Taxpayer/Government</b></p>	<p>Carer role provides government with <b>cheap option for care</b> of those with a disability/aged. This saves the Taxpayer millions of dollars at huge personal physical, mental and financial cost to carer.</p>
<p><b>My role as a former carer of my mother .I am now a secondary carer of others.</b></p>	<p>Despite my genuine efforts to provide for my post caring work; when Mum died, I was empty. <b>I only existed in relation to my mother and her needs.</b> I had no other identity or role in life.   I once read an article by a former carer entitled “why I divorced my paraplegic husband” and she expressed the same comments.</p>

26/5/08

**Recognition improves self worth. Recognise early, recognise often.**

**Recognise Carers by identifying and supporting the carer at the time of the birth of a disabled child, or the person acquiring the injury, or placement of the person, or the beginning of the caring role. Educate health workers**

**Recognise by Annual Commemorative Carer stamps with the Carer Support Phone Number on it during carers week. ( this is achievable)**

**Recognise Carers by annual funding for carer related Art, Literature and Film**  
Entries could be by carers, and from the wider community.  
E.g. Bud Tingwall's "The carer"

**Recognise by providing better opportunities and incentives** for carer education, IT, correspondence courses, self development, and other education Art workshops and networks to enhance carer wellbeing, and carer personal identity.  
This involves better respite funding and workers.

**Recognise the important role of the Carer by providing  
Appropriate funding for  
action research in order to set up better:**

- Counseling,
  - Information,
  - Education
  - Equipment
  - Networks
  - Support services.
  - Respite, both in home, and other
  - Financial assistance/ superannuation/sick leave
- also
- Employ \*Informed Centerlink staff (and other Govt depts.) with
  - Intelligent up to date **computer programs** to process information swiftly and correctly
  - **Re read recent Australian Carer research** many of the answers are already waiting for you

- ask any carer about Centerlink staff and Centerlink computer generated information and they may scream.

26/5/08

**The barriers to social and economic participation for carers, with particular focus on helping carers find and retain employment.**

**Isolation vs. support: A Carer who participates in wider society is happier and healthier and more productive in their caring and other community roles**

<p><b>Poor Carer Physical and Mental Health</b>, and information and availability about support services. <b>Respite</b> to enable Carers to access services Carer Fatigue <b>Ref: Existing research on carer health CAV</b></p> <p>Primary and secondary school education to cover topics such as self worth, health and carer issues.</p>	<p><b>Education of health professionals</b> about carer health research, needs and support services. A <b>computer program</b> for health professionals ( similar to one for about diabetic checks, pap smears etc) that makes sure carers get regular health checks and information about and referral to services <b>Realistic Respite</b> to enable carers to access health and education needs.</p>
<p><b>Real Poverty and Lack of services</b> within some geographical areas, or specific ethnic or language groups.</p>	<p><b>Social justice for all members of the community</b>, not just those who can <b>afford time and money</b> to go out for coffee. Some Carers are really poor.</p>
<p><b>Community attitudes</b>, devaluation , unequal opportunities relating specifically to women, and generally to carers, the poor, and people with disabilities in society, or people from some social or racial groupings needs looking at.</p> <p>I recognize that while there are male carers, the majority are women.</p>	<p><b>The MEDIA shapes a society its beliefs and attitudes.</b> <b>Women in particular are often denigrated.</b> <b>Just laws, and policing of laws. And appropriate fines. Use of community service as a fine.</b> <b>Education, or re education of some groups within community</b> <b>Religious and ethnic background may shape some attitudes</b></p>
<p><b>Lack of appropriate respite funding and support services</b> to assist carers to keep up with just a small amount of paid work when they take on the caring role. This work could increase awareness of personal identity, and general health social networks wellbeing also finances. <b>Ref : research on carer health CAV</b></p>	<p><b>Funding for appropriate respite</b> <b>Funding for training of workers</b> <b>Funding for appropriate institutions/centres.</b> <b>Realistic Funding for respite workers to care in their own homes.</b> ( someone with one elderly parent , may be happy to take another for an afternoon. Similar to home child care.)</p>
<p>Work and education</p>	<p>Practices, and requirements that <b>facilitate carer participation.</b></p>

26/5/08

- **Practical measures required to better support carers, including key priorities for action**

**RESPECT: Real respect for the Caring Role by Government and society**

<p>Check old <b>age pensioners</b> who are carers as well, they may miss out on carer bonus.  <b>Provide much better support for aged parents with adult children</b> with a disability, including the sorting out of financial and guardianship issues.  <b>These aged carers have often cared for a lifetime, not just for a time during life.</b></p>	<ul style="list-style-type: none"> <li>• I have personally helped an aged carer of an adult child who has an acquired brain injury, try to access information and action relating to guardianship , it was a game of snakes and ladders .</li> </ul> <p><b>One single department and person to assist</b></p>
<p><b>Education of the Wealthy</b> specifically, and the community generally , to encourage philanthropy for carer and disability related groups and individuals.</p>	<p>What really is the hourly pay of a person who is on call 24 hours a day in family and living on a pension?  <b>I think there is already Australian research related to this</b></p>
<p><b>Reduce Cost and increase availability</b> of disability aids and continence products etc.</p>	<p>?Taxation  ?Encourage local manufacture</p>
<p><b>Funding</b> for accommodation, long and short term respite, care for a variety of disabilities</p>	
<p><b>Ongoing Funding for Action Research</b></p>	<p><b>Not</b> just research that provides wages for researchers, and produces a report that gets tabled then lost.</p>
<p><b>Ongoing Funding for training</b> at Community, TAFE and University levels , for a wide variety of health professionals needed as support persons, Home care, OT Nurses, Podiatrists, Doctors, Researchers etc)</p>	<p>Provides trained support workers needed.</p>
<p><b>Migration programs.</b> With appropriate training programs including English language.</p>	<p><b>Workers</b> are needed to care for the aging population and those with a disability.</p>
<p><b>Appropriate disability and Carer Allowances.</b></p>	<p>Superannuation and sick leave,(<b>sick carers keep on working at present</b>)</p>
<p><b>Measures based on research</b> to identify key priorities</p> <ul style="list-style-type: none"> <li>• <b>Including issues related to aged parents of adult children with a disability</b></li> <li>• <b>high needs, where 24 hour a day 7 day a week one on one care is needed</b> (respite is lacking in this area)</li> <li>• <b>what number of people with a disability / carers will there be in 2020 ? and do we have ongoing training services and centers for these people?</b></li> </ul>	<p><b>Not</b> just the easiest vote winning quick fix action.</p>

26/5/08

- 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.

Proper research directs appropriate action. I believe There is a moral responsibility to support all sections of the community. Read recent Australian research and act.

Assistance with <b>respite</b> to enable carers to access the internet, information and training.	Information, computers, education <b>Respite</b> to enable this training
Education within the school system so that future carers have information to help them make choices	Educational support for all sections of Australian society
Ongoing realistic funding of Carer bodies	Make it illegal for governments to cut funding if just criticism comes from group (Ombudsman)
Ongoing Research to identify why carers do not access same range of opportunities and choices.	<p>Off the cuff ,I think that</p> <ul style="list-style-type: none"> <li>• socialization of women (attitudes like” you women should do this caring”)guilt, obligation.</li> <li>• the hours and hours caring involves, combined with lack of appropriate support services and personnel</li> <li>• poverty</li> <li>• poor carer health and fatigue lack of motivation, depression</li> <li>• Addictive carer attitudes and Behaviours , Inability or unwillingness of carers to give up the role even for a short time.</li> </ul> <p>i.e. Only I can care for X, no one else can do this task , I do not want help. I have no time for my own care. This is a driven almost fundamentalist belief the carer frequently adopts. This is often combined with <b>substandard support offered.</b></p> <ul style="list-style-type: none"> <li>• Poor access to information and training at all levels.</li> </ul> <p>These may be some of the answers</p>

“All animals are equal, but some animals are more equal than others”  
George Orwell.