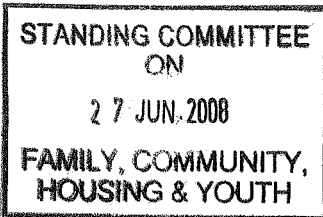


Submission No. 509
(Inq into better support for carers)

A.O.C. 7/7/08



22 June, 2008

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

Dear Secretary,

I 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.

Generic types of assistance are relevant but individual circumstances vary. For instance I am the carer of my 90 year old mother who lives with me in my home.

Regrettably, I do not drive as I gave up driving after a car accident in my twenties. This means that we are frequent users of taxis and when appropriate buses. We have found the Government taxi voucher scheme of immense value in this regard and also the 4 hours package of weekly assistance that my mother receives from a Care Agency.

To obtain an improved understanding of the challenges facing carers and their support needs the Committee should keep in mind the needs of the person(s) requiring care. For instance it is very stressful for a parent to lodge a brain damaged adult child in a nursing home for old people because no other accommodation is available. The same difficulty arises if they require a few hours or days respite care.

I am well able to manage most financial and administrative matters but this must be very difficult for a young carer of a parent. Also, it must be particularly difficult for new Australians and those whose first language is not English to successfully access the available help systems. Knowledge of government and other means of assistance are often obtained by word of mouth from acquaintances.

With the best will in the world the caring situation can still lead to some loss of independence for both parties. One way of easing the situation may be to provide a Middle Level of Care from the Care Agencies (particularly the not for profit organizations). My understanding is that currently only two levels of care are provided i.e. Low Care (about 4 ½ hours per week) and High Care; basically something needs to be done to bridge the gap between the two systems. Some people require palliative care

but they are not strictly High Care and could, perhaps, remain in their homes if they could receive additional care.

Also, professional carers need better pay and allowances. They are poorly paid particularly for the multi skills that they require in such a difficult job. There is a high turnover in the profession because of the low pay and conditions. This means that more training programs are required to train the new staff and experienced staff also need to be kept informed on changes to the caring role. Let me give you a specific example, a Pilipino nurse told me about working in a Nursing Home before she received her approval to work at a hospital in Australia. Some carers were not aware of the need to remove patient's arms from the bed frames before they lifted or lowered the frame that keeps them secure in the bed. As a consequence of this some patients had terrible bruises on their arms.

The role and contribution of carers in society and how this should be recognized

Carers are contributing to society by the very act of caring and are saving tax payers money by undertaking the caring role. Our society already has many helpful volunteers who provide assistance to those needing care for example "Meals on Wheels" but more thought needs to be given to other opportunities for volunteers to assistance in caring roles. There are many people qualified to volunteer for work to assist those needing care but they are not aware of these opportunities, for example volunteer drivers are required to take people to appointments. However, the coordination of these and similar roles requires good management otherwise volunteers can be lost to the system because of frustrations in coordination etc. Better Government funding could help provide such management and encourage more volunteers.

Media publicity with case studies showing real life situations will help show the contribution of carers. Recent television programs were helpful in this regard. Increased Government funding for the Carers Association and similar organizations. Apart from providing assistance to those already in the system increased funding should assist greater promotion of services that are available and make more people aware of how to access help. There are many people who do not realize that they are carers and are entitled to receive assistance in what might be an incredibly difficult situation.

The Canberra Country Women's Association each year provides a gift of \$350 each to three young carers in recognition of their services. This type of initiative could be replicated through other organizations. Government Awards would also help recognize the important role that carers provide. The NRMA and some other organizations provide awards to volunteers. Perhaps, other businesses could promote the role of carers through similar schemes – this could be particularly helpful to carers who are themselves children.

Appropriate professionals to meet with family members at the beginning of the caring role to discuss how their lives will change and the support that the person being cared for will need and also how to support the primary carer.

Maybe a pilot study undertaking a few such meetings would help determine whether such meetings would be helpful and whether some form of agreement could be drawn up between family members and an appropriate Government Agency suggesting workload divisions including what Government assistance would be available. This of course would be a very sensitive issue. There is a very steep learning curve in becoming a carer and time constraints on reading through reams of paper associated with this role and the numerous forms that one has to fill out. Nor, does one necessarily have the expertise to work out how other family members are affected by the change in circumstances.

We read continually that in Western Society there are now more old people and that there is already a shortage of people available for their care. School children and even members of the general population may not be aware of this and that society has obligations to assist others particularly the elderly or those disadvantaged in some way. It can simply be a question of good will and manners e.g. standing aside for someone to get on a bus or carrying shopping on the bus, offering a seat on the bus. People do appreciate such actions.

My mother worked as a volunteer for many years at an Opportunity Shop which helped provide funds for accommodation for people who had been brain injured. One of the schools in Canberra arranged for a couple of its senior students to help out in the shop (a new slant on work experience). This was appreciated by the women who ran the shop and gave the students a clearer idea of the difficulties under which some people live. The girls seemed to enjoy helping and a letter of appreciation was written to the school. More schools could be encouraged to participating in such ways.

The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;

Spontaneity in arranging social or economic activities is reduced. The primary focus becoming the medical, health and social welfare that the cared for person needs. A dual dependency can develop particularly if they are well loved – what happens when the cared for person is no longer with us? How will one cope given that the caring role has become one of the main focuses in ones life!

Government packages of assistance are a great help but a G.P or other medical professionals may make it clear that they want a family member to accompany the patient rather than a paid carer. Sometimes the carer may have conflicting medical or other appointments for themselves. For instance I was not able to attend the Carers Inquiry Focus Group to discuss this submission because I had to accompany my mother to a medical appointment that took four hours. Although, thankfully we were given a lift there and back within her 4 hour package of assistance.

Arranging respite care is time consuming and labour intensive for the carer and others and can be upsetting. For instance my mother has a fine mind but was put in the dementia

area because that was the only bed available. There was no time for me to change this arrangement because I was not aware of the situation until too late to alter it. If this had been explained to me at the time of initial contact I would have tried to make arrangements for alternative accommodation. I was not able to change the timing because I was scheduled to have an operation. So Government Agencies need to clearly explain the type of accommodation available when the initial contact is made.

My mother was deeply upset about being in a dementia area although she probably made lots of friends because she was the only one who knew the combination to unlock the door to the other areas! Furthermore, during the two weeks respite care she had unwanted visits by six different dementia suffering male patients. Admittedly, they were harmless but it must have been alarming for her when she returned from lunch one day to find a strange man in her bed.

Let us look at the workload from the carer's perspective when respite care is being arranged:

- . telephone appropriate Government Agency to discuss timing and available facilities,
- . contact the respite facility recommended by the Government Agency to request application form and confirm dates;
- . complete application form as best one can,
- . make appointment to see G.P. with the person being cared for;
- . accompany the person being cared for to the GP for medical clearance,
- . assist GP in completing the form and arrange for them to sign a form confirming that they will, if necessary, visit the respite facility to see their patient;
- . pay G.P.
- . go to town to collect Medicare rebate
- . Discuss with Chemist the medication situation and arrange for them to provide a form for the Respite Nursing Home detailing the patients medication list so that medication can be signed off when given to the patient,
- . arrange for Webster pack to be delivered to the Nursing Home;
- . send completed forms to the Nursing Home,
- . liaise with the Nursing Home re suitable time for a meeting,

- . attend preliminary meeting at the Nursing Home with the person being cared for to check forms and inspect the facilities,
- . select clothes; write name tags and pack clothes for the person being cared for to take to the Nursing Home,
- . take the person to the Nursing Home and check out the room to make sure the person being cared for can close doors and open desks and switch on the television etc. In my mother's case the door was difficult for her to lock as will be seen from the above mentioned visitors.
- . arrange for a telephone
- . pay the Nursing Home
- . arrange for friends or other family members to visit the person being cared for.
- . bring the person home on completion of the carer's break.

Sometimes one needs to get away for a couple of days to see friends or visit interstate children and grandchildren. The work required by the carer to arrange this respite means it is hardly worth the effort to go away for just a few days as it can take a couple of days work to arrange the respite.

The administrative and bureaucratic process needs to be simplified, but how? Opportunities for a professional carer to stay overnight in the home whilst the carer is away for a few days could simplify the process.

Employment - daily visits by professional carers to the person's home may help. However, employers and colleagues including those in Government Departments, understandably, often resent the number of telephone calls an employee may receive regarding their carer role and the time taken when they have to leave the workplace at short notice to attend the needs of the person they care for.

Seminars and information booklets may give a better understanding of the role the carer plays and the support they may require. This would be fairly easy to arrange in the Public Service. Nowadays, because of improvements in communications there are more opportunities for people to work from the home, opportunities for carers in this respect should be encouraged and where possible part-time employment or job sharing arranged.

The practical measures required to better support carers, including key priorities for action;

- . overnight care in the home to allow carer respite,

reduce the workload required in arranging respite care;

special holiday accommodation and travel assistance so that the carer and the cared one can go to for a few days break – this could be means tested as some people would be prepared to pay for such assistance. Opportunities for carers to employ a person from a registered care facility to accompany them on a few days holiday,

a government scheme facilitating insurance policy to cover the employment of such a person by the carer;

perhaps, the ACT Carers Association may be aware of some firm that would be interested in contracting for such holidays,

better pay and allowances for professional carers and more funding for training;

free local bus travel for the carer and the cared one – it is difficult assisting a physically disabled person on to a bus, sorting out change and getting the person seated before the bus takes off. I understand that in the U.K. and Ireland people over 60 years of age do not pay on local buses and that people who have a carer in the U.K. have a special symbol printed on their bus card to indicate that the carer can travel for free;

training for bus drivers – frail people to be seated before the bus moves. Most elderly people travel after the peak hour traffic is over. It would be kind if bus drivers helped people with walking frames. Some bus drivers do this willingly; others consider it is not their responsibility or that they will be sued if something goes wrong. Some bus passengers help with walking frames etc. People become very isolated if they cannot get out and about. Many people cannot afford taxi fares and have no family to help them,

the taxi subsidy scheme is an excellent government initiative - more people need to be aware of it and a higher rebate provided for those who are financially challenged,

assistance with taxation returns. This carer role is difficult when one has had no previous experience of the family finances of the person being looked after. I found the Taxation Department helpful after I explained the situation. Perhaps, there could be a special area of the Taxation Department that could assist others in this way. Also, there are opportunities for retired specialists to assist as volunteers.

the need for family counseling at the start of the caring role. If family members did not wish to undertake such a session, perhaps, a letter explaining some of the pleasures and difficulties of the caring role and the need for support by family members could be helpful

and

bathroom and toilet modifications, ramps, special beds etc. to enable the person to remain at home or in the home of their carer. Some appliances are inexpensive such as a “grabbing stick” this costs about \$55 and helps people to draw curtains and pick up objects that they have dropped or are too high for them to reach. A gift from the Government or business organizations of a “grabbing stick” to needy people could prevent accidents and thus reduce medical cost to the State.

Strategies to assist carers to access the same range of opportunities and choices as the wider community,

Easier excess to respite care in the home (i.e. overnight stays) and simplification of the process involved in obtaining respite care at a Nursing Home.

Government packages of assistance are helpful and my mother and I are grateful for the services provided by Goodwin Aged Care Services and South Side Community Services. More people need to be aware of such assistance – people who are not linked to Centrelink may find it difficult to learn of the opportunities already existing to help them. We learnt about the assistance because my mother had worked for many years as a volunteer for various non government organizations. Again media advertising could help or an information paper delivered to the home of people of say above 60 or 65 years of age so they can keep for future reference.

I hope that the above is of help to the Committee Inquiry. I look forward to reviewing any recommendations you make to improve life for Carers in Australia.