From: James

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

AOC 16/7/08
Submission No. 803
(Inq into better support for carers)

Monday 23rd June 2008

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.

Dear Secretary

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

I am submitting to the inquiry because I am a Primary carer for my wife who has had MS for some 8 years.
I attend as a carer at the Shepparton based 'Goulburn Valley MS Support group' that meet monthly at Ave Maria facility where I have attended meeting for a number of years. I have assisted in arranging guest speakers to some of these meetings.

I am also part of and involved in organizing activities and speakers for the 'Tatura Carers Group' that numbers around 12 at our meetings. After our last meeting on Monday 23 of June 2008, after our guest speaker had finished speaking to the group and departed, I read the letter sent from Carers Vic. and asked the group for their response to each of the four main points. This submission will have a considerable content from the Tatura Carers Support Group as well as some of my own ideas. At present the needs and requirements of all the members within the group are different and varied. We meet on a monthly basis at the Tatura Community House.

The background of Tatura where this group meets is of a small rural town that is a very community based, has good facilities, shops sporting facilities. The town population is approximately 2800 + people with surrounding farms and industries. The town started out when pastoralists moved into the area in 1850s, but was officially established as Tatura in 1874. Industries today that employ larger numbers of people include Murray Goulburn Water, Department of Primary Industries, Unilever, Tatura Milk Industries, Abattoirs, Child care, Primary Schools, supermarkets and several Engineering firms.

The impact of the drought is a factor that has affected many families and businesses within the surrounding area. The cost of fuel and food is affecting presently increasing and many farms with crops sown are dependent upon solid rainfalls to help them get through. Tatura now known as water wheel country, however the reality is that irrigation water is piped away from this and other fertile farming area is, well known for surrounding orchards and dairy farming food bowl where Tatura is located. This is a critical factor in the thinking of local people and tends to add to a sense of loss among so many other factors affecting people's lives in the area.

I attended another carer's meeting (a group of 10 people, including myself) in Shepparton between 10 to 1 pm on Tuesday 24th of June at Southbank (Shepparton Art Gallery). One Carer belongs to

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the Shepparton Generalist Carer's Group and two of us are from the Tatura Carer's group. The others belong only to this group so we discussed these Government terms of Reference for the Inquiry into better support for Carers.

I also attend one other group that is a 'men's ' carers group and while small in numbers, this group meets approximately fortnightly and meeting a need for carers who are men who can meet and 'have a chat over a cuppa and light refreshments'. The very fact that such a group is running and is a new imitative in this region and is important as the only other venue is the Men's shed that does run in Shepparton, which is more activities based at their shed and perhaps for older men who perhaps are single and do not have a shed or workshop.

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

As a carer, I feel that my role is…

- As a carer, I feel that my role is an extremely important and valuable contribution to society. As a carer, I can imagine the difference for someone with a disability or life long disease some 50 years ago who lived in the country area on a farm. The husband could not afford a lot of time and limited knowledge and drugs were available. As a result the mother of one of the carer's in the Tatura group died at a younger age due to these factors perhaps lack of support for the family and this lady was bought up by her aunty as a result when her mother passed away when she was around 8 years old.
- I assist my wife in putting on shoes and socks at times, preparing and cooking meals, organising the daily washing and drying of cloths, assist in shopping and paying bills on the internet. Collecting medications from the chemist and taking medications at appropriate times is also important, although at times my wife often reminds me that at a certain time I need to take my medication. Helping her to get her lower legs into and out of the car. Who would take away the valuable years that she has in helping raise our three daughters. How can you put a value of the personal love and care that she imparts and imparts onto our children? She is there to council, listen to their problems and spend time with them. She cannot be at all of their activities but takes a great interest in all they do. She gives them direction and correction when needed.
- Often carers are also on some form of medication due to their circumstances or health. Carer's often care for a person who has a disability, is frail, challenged with a chronic condition, terminal illness or even mental illness. Often there can be a mix of two, three or more of these conditions together that the carer has to respond to in caring for a loved one. This is extremely demanding or wearing upon a person and can be exhausting for a carer who has little time to escape the routine of constant caring. If the carer is not aware of their own need to stay fit, healthy and active physically, mentally and spiritually switched on then the carer may well be at risk as well as the one cared for.
- Carers often provide a unique service that is difficult to fully recognise, and is often unpaid for the total time and care given in support for friends, family and or loved ones.

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- The effect of a chronic disease on a person's health and life can vary dramatically. It can change quickly over time having a very mild or little effect on the individual to becoming a very aggressive, severe disability. i.e. **dementia**, little shaking or tremors to severe shaking or attacks, **multiple sclerosis (ms)**, would appear healthy (as normal) to severe aggressive changes in health where lack of movement, loss of mobility, restricted or little sight, incontinence and sleep disturbances and exacerbations occur frequently and are severe. The carer is often a family member who has no medical training but has to go with the flow as well as learning 'on the hop.'
- Often the community may perceive that people are afflicted are in their later years, often retired or disabled. We do not seem to have adequate facilities, especially in country areas for younger people who need hospice or support away from their home where the carer usually lives and so can end up in a retirement facility or hospice where the vast majority of people have dementia or other sever disabilities and are elderly. This is only highlighting the need for better planning of care and hospice facilities and within communities. I believe that the best types of care come from independently run community based organizations that have no side agenda's or vested interest apart from the welfare of the people within the community and not just the bottom line to make money. (as important as that also is.)

If the carer is not there, then the quality of life for that person will be severely affected. The world can change dramatically when you suddenly find out that you have a life long illness and have to stop work, not accepted back into the work place any more and your role in life has now changed permanently. What does the future hold? Can I now do all the things I used to with my children? The carer for this person also can have simular changes occur in their life although their life now largely revolves around the one they are caring for. How has this influenced upon their life especially if a loved one? Financial concerns, debt, loss of esteem, self-doubt and lack of support from other members of the family can be a major concern .There could be 10 years wait to gain access to their superannuation that would be beneficial for a child that requires particular equipment or facilities that the parents cannot afford to purchase living on one wage. The carer life changes to one of organizing appointments and interviews, filling out applications, appointments with doctors, specialists, health professionals, medical boards, police, JP's and Centre link, etc for testing, written proof of identity, counsellors, etc.

Carers contribute an untold and often selfless giving to those who are vulnerable, needy and afflicted within our society. Often the fear of the unknown for those being cared for is foremost in their minds, especially if they become so dependent upon their carer to the point of manipulating circumstances that the carer could struggle with their need to have time away from caring because on the intensity and continuity of constant caring for a loved one. Recognisition of the role of the carer is something that should be up there with those reaching 100 years and receiving a letter from the Queen or Royalty. Perhaps a carer's Labour day scroll to recognize the extent of change in lifestyle, commitment to caring for another and dogged perseverance in the face of adversity while retaining some sense of humour, balance and sanity at emotional and critical times. The French cried out 'Liberty, Equality and Fraternity' and should be changed to Long-standing service, Efficiency and Patient Faith or Loving Care, Emotional Support and Faithful Service.

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CONTACTS: Points of contact, information and personal contacts made from carer's groups and support given from government or private care organizational groups like Family Care, Villa Maria and Carers Victoria are the voice and support to carers across communities as well as the high profile MS group who are also working hard for those who are MS challenged. This kind of networked support and relevant and accurate help when needed is so important. Free call access to information, medical advice and personal advice is vital. Counselling and family assistance through the local doctors is important for rural areas in drought but also where chronic conditions or terminal illnesses occur across the nation.

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

As a carer, I face the following problems …

- Carer's are often the only one that helps to hold families together. Nurses are qualified and tend to 'be run of their feet' with so much to do in hospitals and do an awesome job of care for the patient plus much needed attention to detail with medicines for patients. Yet it is the carer that often knows and keeps a cross check of the various medications, procedures and needs of a patient while in a hospital or visitation to specialists for tests or support. Sometimes a change of shift can bring in someone new who may be working at odd times in the morning and think that medications have not been given.
- Carer's often have to work harder in caring because it is 24/7 within in 4 walls of a home or respite or medical ward to maintain an ongoing care situation for a person which could have a myriad of different needs and requirements. These could vary widely and could be a few or many of the following; communicating by sight or touch, sign language. Preparing to give correct medications to be taken at particular times, bathing, cooking as well as cleaning, paying bills, shopping, house maintenance and gardening to mention a few. You can access 'home help' in meals or wet areas and different jobs required at home through the council and other organisations like silver circle but all come at some cost, even though this might be minimal.
- Some barriers for men may exist where they have little support from other men because they are not willing to or are unable to join in a support group due to their manly up bringing and see it as weakness to be involved.
- Economically, many carers' are on a pension or on a limited income and so may not fit into the accepted work place environment due to limited income. They have little available cash to go out or be involved in golf clubs, join a gymnasium or any of a number of service groups if indeed they would have energy or time to do this. A carer will only stretch so far.

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

As a carer, I need help with …

- The leaning curve sometimes is steep. Assistance is needed by many, because there are so many complications and variables with specific diseases. Doctors and hospitals who are treating people with newly diagonized conditions should make them aware about what help can be given can be given through these particular support groups. Assistance or advise over the phone, medically but also how to cope and learning to live daily is also very important but also at more of a local level to give their carers and family contact points for assistance through local support groups.
- I found that carers can benefit and be advised to attend (for those who could) a 6 to 8 week course as I have attended in Shepparton run by 'family care' that takes carer's through a range of teaching/ interacting and practical group information and social skills and professional help run at suitable time and venue (RSL room) to assist with health and wisdom about issues that carer's deal with. This group still meets and has a session on grief and loss coming up.

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

I think the Government can better help carers by ...

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- Education through local (relevant) speakers at the local (Tatura) Carers group is important. Assistance with some funding for resources, activities and other type needs as they arise. This might include the rent for the payment of the room which is currently paid out the carers own pockets.
- We need greater flexibility with some time release as a group so we can go away for a weekend as a group within the local area to have some 'time out' collectively. This would be good every 6 months.
- One member suggested that Kevin Rudd could drop in and attend a carers meeting as a guest speaker or just as a one of the members. Nothing like going to the top.
- Suggestions like reduce the tax for carers on their superannuation funds with the ability to access some of the funds as earlier times to ease the financial burden for children or elderly. The point is they heavy already paid tax on this twice and should 'be enabled' to have access sooner when this is needed and not later.
- Another idea was to have a special fund for carers where their superannuation and funds 'can be linked' to other funds that have been left to wills and estates so that special needs can be met quickly.
- Need to put more funds into access of beds and care in hospitals.
- Greater flexibility in rebates for those who show through private insurance that they use up their extras well before the end of the year so that there is little in rebates for them due to the care required.

Thank 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 sincerely

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*James*

*26th June 2008*