

**Parliamentary inquiry:- Better Care for Carers**

Submission from:-  
John

..... *the Committee will inquire into and report on:*

- *the role and contribution of Carers in society and how this should be recognised;*
- *the barriers to social and economic participation for Carers, with a particular focus on helping Carers to find and/or retain employment;*
- *the practical measures required to better support Carers, including key priorities for action; and*
- *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*

For those with needs requiring support there are often two categories of carers, first those who will often come from an Agency and receive adequate training, support and more to the point an adequate wage (although some would question that there is room for improvement on this last point), and the other category - family Carers. What this enquiry is aimed at is those friends and family who provide support for those in need, often because of reasons of obligation who are, for the purpose of this enquiry, **Carers**.

I would however, note the supporting arguments for having an inquiry in the media release and the slightly different version on the web site noted several points not directly mentioned in the terms of reference, unless you push to the limits the somewhat general terms above. While you appear to understand them I believe elaboration from the coalface may well put the issues in more focus and some of these I will refer to on the basis that they are part of your preamble justification for the inquiry.

I believe the terms of reference should have also specifically included the Economic and Social impact of Carers on Society, and at the risk of going outside the terms of

reference I will therefore include some comments on this important aspect of being a Carer as a part justification for significant increases to Carer Allowance.

I also note the somewhat naive list of specific groups of Carers failed to include issues of being a **Long Term Carer**. On the basis of this being probably the most significant group of Carers with special needs, with those in the sub groups of new carers, younger carers, older carers, Indigenous carers and those with multiple care responsibilities often also falling into this category with a resultant significant increase in the way they are disadvantaged.

There is also a need to investigate personal Health needs of Carers and how being a Carer negatively impacts on their Health.

While I have embedded recommendations within other text (***Bold/Italic***) I have also summarised them later.

### **My Story**

As my mother aged, my sister who was a qualified nurse found she increasingly needed to care for our mother. On some occasions when my sister and her husband utilised respite services in a low care hostel the one they sometimes chose was close to our residence so we could more easily visit her and monitor her condition while her normal Carers were gaining much needed respite. My sister however commented that while the respite was welcome she frequently took a number of weeks to eventually return my mother's health to what it was before entry to the facility. This is apparently a frequent comment, while respite is welcome it often requires a significant effort to prepare for, and later to overcome the negative health repercussions.

When eventually our mother needed permanent accommodation in a high care facility my wife spent a good deal of time driving my non-driving sister around nursing homes and discussing the good and not so good points about them and making sure they found one that met their standards, both in quality of care and also being readily accessible from my sister's residence by public transport, despite unwelcome pressure from a bureaucracy that paid little attention to their specific needs.

Once our mother was in the Aged Care Facility of her choice, my sister assisted in the formation of the Victorian Carers Association and went on to represent Australian Carers at a world conference of Carers in London. Several weeks after returning from the conference our mother passed away. My sister has however maintained a keen interest in understanding the difficulties of Carers and their need for support, particularly as it now applies to my wife and I.

My wife's mother is growing older and is in more need of assistance. In 1984 when we purchased our current property it was with a requirement for room for a Granny flat for Mum in the back yard, and this was built shortly after we moved in. Initially despite a severe deafness she maintained some independence, walking down the street to the shops and preparing her own food and caring for herself. Gradually she became less able to care for herself, becoming legally blind through macular degeneration, requiring our assistance first with shopping, then preparing her meals and providing increasing levels of care. Since late in the 1980's she has been a

closer and closer part of our lives. Several small strokes in late 1990's heightened her dependence on us and she has been a necessary part of all our holidays, in 1999 this even including a six-week holiday to England, Scotland with a side flight to Zurich, through the Alps to Italy etc. Her wheelchair had enough frequent flyer points for an overseas trip!

Fortunately as a former Commonwealth Public Servant I was able to resign/retire in May 2001 on a just adequate pension and now have time to assist my wife in caring for her mother. The need for assistance has gradually, but significantly, increased over the years; being a Carer tasks often creeps up on you in intensity!

Our last period of overnight respite for Mum was in 2002 when in the first week she fell and sprained her ankle, and during the second week she fell and broke her wrist. On eventual departure at the end of the respite period the director of nursing at the nursing home indicated they would not accept Mum for respite again, she was too difficult to manage (or were they worried about their legal liability?). The supervisor of our regular day care respite counselled us that Mum was 'an accident waiting to happen' (in other words if she was put into high care permanent accommodation she would have falls and this we felt, would probably cause her death - in our estimation probably within weeks rather than months)! Since that time we have had only Day Care respite, usually four hours a week. Even when Mum has had short periods of hospitalisation we have had to stay with her to prevent her from trying to get out of bed unassisted, on one occasion we were with her in hospital 24 hours a day for several days because of her restlessness.

Later this year we are looking forward to her turning 102 and still living with us. Our bedroom is the sitting room for her Granny Flat because of the need to still closely supervise and assist her at night; there is a motion sensor and alarm over her bed that will warn us whenever she attempts to get out of bed (one night that was about every ten minutes all night till seven AM and two Stillnox). She now requires assistance with feeding, toileting, showering, dressing, mobility and medication. Any activity where she is required to stand is only undertaken when both my wife and I are present. Mum has for about ten years had a High Care Aged Care Assessment status.

We usually try to get Mum out of the house every day, either just to local suburban shopping centres, to short holidays either to our holiday house on Phillip Island, or to my sister's place now in Hepburn Springs. My sister understands the critical need to give us time out from caring as well as having someone else who understands to talk to. My sister will often instruct us to 'go down the street and do what ever you want to for a few hours', while she supervises Mum, who these days spends much of her life in bed. We also visit an elderly friend in Sydney, We have our selected rooms at selected Motels to break the journey up; we usually go at least twice a year and Mum still seems to like the drive up and down the Hume!

My wife and I otherwise only go out when the other one is available to supervise Mum. Even on Phillip Island we only walk on the beach together when the weather is mild enough to take Mum, and the sand is firm enough to wheel the wheelchair [Stop press, Thursday 29 May 2008 a friend from the local Uniting Church supervised Mum for two hours while we had a walk on the beach and a coffee in town!]. Note - high

care day care is not available in Phillip Island as it is in Melbourne. Medical and hairdressing appointments and occasionally even our own ability to get to the toilet or have a shower is when Mum is settled or supervised by the other – Caring for us is now a two-person job. I am conscious that of recent months I have been significantly curtailing my outside activities because of the need to further assist my wife, dropping my participation in church, hobby activities and the like.

We still usually get four hours a week respite at a Day Care facility at Uniting Aged Care at Strathdon in Forest Hill. This is brokered by the agency 'Uniting Care Community Options'. This latter agency provides funding for support services to those with disabilities and to the frail aged living in the community. Those who participate in their programs they call participants and they have a Participants Committee of who meet regularly to provide feedback on services and to design ways of eliciting feedback on services from other participants. I have been a member of that Participants Committee for over a year and as a result been confronted with the needs of other committee members and other participants, some with disabilities living alone with support services but the majority are either parents of children with disabilities or those who rely heavily on family Carers.

I think I am qualified to speak on Carer issues; we care for my Mother in Law in a way that seeks to give her an interesting life to the best of our abilities. I also see the need to care for my wife, to support her in a way that enables her to continue in her role of a Carer. I have discussed many issues with my fellow committee members at the UCCO Participants Committee and with my sister; I have a keen interest in assisting developing systems that will better support Carers in the future.

### **Response to Terms of reference and other related issues.**

#### *The role and contribution of carers in society*

Carers, in the words of the Kevin Rudd during the election campaign, "Save society a bucket full of money!" (Or something like that). For many years Mum has had a High Care Aged Care Assessment and entitled to be in a High Care Nursing Home where I believe she would be costing the Government around \$100 a day - if she survived. I agree with the now Prime Ministers Assessment, Carers save society heaps.

Carers also make a significant contribution to maintaining Family Values in society. If we did not have the example of those who are going the extra mile to support family members then society would be worse off.

#### *How this contribution of Carers should be recognised;*

Some carers may qualify for Government assistance by providing basic support for someone who needs it. I have however noted the increasing demands on my wife and I as carers in supporting an aged person who is becoming increasingly frail. For Mum it is all-downhill; the list of what we need to do to support her grows, things she was able to do several months ago now require more and more assistance from us. We have long ago passed the basic threshold for what it takes to qualify for Government support, however we are still only paid the basic pittance of about \$7 a day in Carer Allowance.

I believe carers Allowance should be indexed to what it would cost to institutionalise their patient. ***Carers Allowance should reflect honest commercial payments for the services that they provide.***

At the moment I would assume all older patients being supported by Carers should have an Aged Care Assessment. This assessment is already relayed electronically to Centerlink. If it was decided to link Carer Allowance to at least this assessment for a multi tiered Allowance, the assessment and structure is already happening and is in Centerlink's system. It may be that younger patients may also need to be more formally assessed and the range of assessment levels examined or expanded. ***The basic structure to assess the different levels of Care that is needed - already exists; Carers should receive increased levels of Allowance for providing higher levels of Care.***

Meanwhile in wider society I wonder how many people simply cannot financially consider becoming carers. How many people are put into institutions at significant cost to Government because the alternative is for someone to become a Carer and only get the stingy Allowance of \$7 a Day. ***If there was an approach to funding Carers at a level relative to what they contribute there may be a significant incentive for people to take on the Caring role and reduce the need for institutional care.*** This may well reduce the need for establishing and financing institutional care, and increase the recognition of the importance of Family Values.

I note a news item reporting a recent submission to the Productivity Commission hearing into paid maternity leave in Perth where it was noted by Professor Barbara Pocock from the University of South Australia who says reservists are paid about a \$1,000 a week, which is nearly double the minimum wage.

"Why would we pay women who are home with a new baby, or fathers that are on paternity leave nearly half what we pay people to learn to operate in the army reserve, for example," she said.

"We think there's a good case for taking the model of leave to train for military reserve, and to take that forward for paid maternity leave at a decent pay rate for an extended and appropriate period of time."

***I believe these arguments put to the Productivity Commission on Paid Maternity leave by Professor Barbara Pocock would apply equally to at least those Carers who are caring for patients with high care needs.***

Before someone butts in that Carers can also get a Carer Payment I would make several comments on that. *First* historically it was the only Centerlink Payment of this sort that insisted that the recipient had to work to get it. The mud that was thrown when 'Work for the Dole' was suggested is nothing compared to the Shit that Carers have to put up with (literally) to get their pittance. *Secondly* it can only be acknowledged as a pittance. It is means tested on the whole family income, for anything extra that a partner earns, the Carer payment reduces to make sure they remain second-class citizens. Some years ago my income slipped slightly below the Carer Payment threshold and my wife got a Carer Payment, because of that our son at School got Austudy which put our family income over the threshold so my wife

then lost the Carer payment! We have lived for several decades as a compulsory single income family because my wife was a Carer. ***The Carer Payment could be totally scrapped and what Allowance all Carers get should be related only to what they do, and related in an honest manner to market rates.***

Carers need Superannuation! Being a Carer on a Care Payment or Carer Allowance does not even qualify to participate in the much publicised 'Superannuation Co-Contribution Scheme'. Even if Carers have the time or the emotional energy to find some employment, the Co-contribution is only available if your 'work income' is a suitable proportion of your total income! ***There should be immediate acknowledging that being a Carer and that the Carer Payment and Allowance is payment for work for the purposes of the Superannuation Co-contribution regulations.***

On top of that the Government should treat Carers as legitimate employees and pay the compulsory Superannuation contributions, preferably backdated for the many years that successive Governments has been avoiding complying with their own legislation. Without superannuation like the rest of society, today's Carers are tomorrow's second-class citizens. ***The Government should make compulsory contributions to the superannuation funds of carers.***

We are approaching the end of the financial year and once again Carers with social isolation are poorly equipped to take advantage of changing financial and superannuation regulations. This may relate to financial planning for the Carer, or on behalf of the person being cared for. Many carers may get an opinion or ruling one years and be unaware of changing regulations, often in areas not covered by Centerlink. Even the Centerlink newsletters may not adequately cover individual situations, if Carers get time to read and absorb it. ***There is a need for flexible access and support for financial counselling for Carers.***

The current mode of financial support for Carers is based on an outdated Pension mentality, that is to strike an Allowance at a very basic level (and no-one understands why it is at that very low level) and if needed, put people on a means tested payment/pension to try to shut them up and let them live in poverty. No wonder the former treasurer stated that Care of an Aging population is a growing problem. That mindset was that the only solution for aged care is institutional aged care, that no one in his or her right mind would voluntarily become a Carer. Just pay the big business institutions to do the job in an impersonal way (and I have the utmost respect with the way some agencies attempt to provide the care within the financial constraints they are under, maybe additional and more flexible funding is needed there!)

The problem is that no one chooses the job, the job chooses you. My friends on the participants committee include those who discovered in a maternity ward or soon after that they then had a child who had a significant disability, those parents moving into retirement who get a phone call that their adult child has had a stroke requiring constant care, those people who hear the diagnosis that they have a seriously disabling illness and will need to rely on others for their care. We find that our parents are becoming unable to care for themselves. People find their only option is to become a Carer, or to throw family values out the window and abandon the family

member to what is seen as a sub standard institution, at significantly more financial expense to society, and especially the significant more moral expense.

***The current level of financial and other support for Carers seriously undermines Family Values and discourages people from becoming Carers.***

*Barriers to social and economic participation for Carers,*

Time! Being a Carer is a high priority for your whole life. If being a Carer was more seriously recognized financially then they may be in a position to be more flexible in their social participation in life. Carers who are getting a pittance frequently trim what can be seen as non-essential social activities. Participation in social activities however results in a better life for the Carer, improved mental and physical well-being, more exposure to outside ideas and thus better decision making in their role as Carer. I cannot remember the last time my wife and I even went to the pictures or had a significant social outing without either having Mum along, or watching the clock as to when we had to collect her from respite. Lack of social contact is a recipe for significant physical and mental health problems. ***There is a need for better financial and other support for Carers and this should bring with it more access to necessary social activities and improve the role of the Carer and their quality of life.***

There have been (rare) examples of Carers willing to finance additional care for those they support, however on investigation it was discovered that this reduction in hours that they provide care would have made them no longer eligible for any support. Carers should be able to 'Job Share' the task with other Family Carers, or by contributing to the cost of agency support. ***The provision that 'if the person is out of your care for a set number of hours' then you do not receive any support - should be eliminated.*** For many years my wife and I have supported each other in the role of Carer. For most of the time my wife received the Carer Allowance and Payment, however as she is now eligible for an Aged Pension we have chosen to get her established on that payment and I am now officially the Carer (overall no change in total financial support or our caring roles), in reality we have both shared the role for many years and as noted above some important tasks require both of us to achieve. ***It should be first established that a person requires care, and then if a team of people share in providing that care then the financial support should be able to be apportioned between them based possibly on the number of hours of care required and/or the care provided by each Carer.*** Just it may be difficult to design the system or administer does not mean it should not be done.

For many people in employment they live caring primarily for themselves however Carers need to always weigh up the needs of the other person in their life that rely so significantly on that support. This places significant stress on those who need funds from a part time job to exist and can result in loss of employment. Comment is made about the need for more flexibility for parents of young children, the same should be recognized for Carers. ***Carers' need for flexibility in employment should be recognized and may need to be more rigorously supported by anti-discrimination provisions.***

*Helping Carers to find and/or retain employment;*

Carers, as noted above need more flexibility in their working conditions, probably supported by anti-discrimination provisions. However for Carers, particularly for long term Carers as discussed later, maintaining job skills or developing new skills is part of an essential long-term plan, not something you can get to think about just when the Caring role stops. Continuing education can also be seen as an essential social activity. Education may also include developing skills relevant to their role as a Carer. ***Developing and maintaining Job and Carer Skills should be recognized as part of a long-term life plan and the Carer should be encouraged with financial and respite support to participate in continuing education while they are still Carers.***

*Practical measures required to better support Carers*

As above, ***Carers need more financial support, better socialization and continuing education. Society should 'Care for the Carers' and Carers should be able to realize they are affirmed and supported by society.*** (Not treated as second-class trash as they are now!)

*Strategies to assist Carers to access the same range of opportunities and choices as the wider community.*

Each Carer is different, as is each person under care, and because of the differing needs of Carers many will require a specific response to this question.

***Individualized counseling and support services as well as access to support services that are flexible should be available to all Carers.***

*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*

As I have suggested above a comprehensive improvement in support services for Carers should be the basis for a response for this question

*Special Interest groups of Carers*

As noted in the official preamble .... 'there are needs of particular groups within the caring population including new carers, younger carers, older carers, Indigenous carers and those with multiple care responsibilities'.

To this list I hasten to add ***Long Term Carers***. It is acknowledged that Carers are disadvantaged in participating in the social and economic life of the community. I would suggest that the outcome of this disadvantage is not a direct relationship with the duration of the time spent Caring. Today's society, economic and social, is changing and for anyone segregated from these changes the impact compounds negatively for additional time spent out of the loop. My wife last had real employment before our marriage in an office using a typewriter, and if she sought employment now with little computer understanding or skills she would be unemployable in that field. Fortunately she is now of Aged Pension Age and although we have a significantly less nest egg to live on than might have been hoped for we realise that retirement on what we have got is our way of life. Our participation in sport is non-existent; recreation is dovetailed in to our Caring role only occasionally. All other activities come after Caring.

The longer a person is a Carer the increasingly more disadvantaged they become. ***Cumulative Long service leave and sick leave should be added to Carer's***



**entitlements so that when they are no longer Carers that financial support will continue when they are better able to take that leave.** Carers may require medical treatment that has to be postponed until after they cease to be Carers, this should be also supported by paid Sick leave. This could be reduced for periods of respite taken, although as noted sometimes respite is a double-edged instrument, maybe realising that basic respite of several weeks should not reduce the accumulating long service or sick leave.

Another special group of Carers are those who live in country areas. As noted before, while we can access High Care Day Care respite in Melbourne, we have been unable to locate any accredited provider of this service on Phillip Island. **Services in rural and other areas should be surveyed to identify shortfalls in support services and steps taken to provide this support.**

*Personal Health needs of Carers and how being a Carer negatively impacts on the Health of Carers.*

Carers frequently have the necessary mindset of putting themselves last. This is often because they are so financially disadvantaged and time out to look after themselves is a luxury some ignore. Because support services are so inadequate and inflexible Carers can put off things like preventative health care for themselves because there is no one to replace them when they need it and health care is not available when they have time to access it. As Carers are a part of Society it is false logic to suppose that they are not susceptible to the same health problems that others experience. Because they are more prone to ignore warning signs health problems can grow to a much more significant cost in the long term. The number of Carers who have died 'in harness', their lives cut short significantly because of their role as a Carer is a blot on our history. **Carers need better access to health care, and should have respite and support services so they can access the health care when it is provided.**

Carers by nature of their relationship with the person being cared for can often find themselves with unexpected new tasks, lifting and supporting the patient, dealing with dementia or other, having violence directed at the Carer. Carers find they have lifting induced injuries or aggregation of other medical conditions because they are Carers. Carers often work alone with the patient, and the peer or managerial supervision or support that Nurses receive is not readily available. **There is a need for better and continuing education for Carers tailored to the changing tasks and roles they take on, as well as access to aids and equipment to assist in their tasks. There needs to be proactive access to services such as Occupational Therapy and other resources to equip Carers to perform the changing tasks they encounter.** As noted under Long Service Leave, paid sick leave for medical treatment may need to be taken after the Caring role ceases. My wife is many years overdue for surgery because she has had a continuing role as a Carer, when we no longer care for Mum is the earliest we can contemplate this. Fortunately in 2003 when I was diagnosed with Prostate Cancer (and having another medical related emergencies at the same time) my wife was able to Care for her mother alone while I was in hospital, and recovering from the surgery. For some Carers, the prospect that they may be incapacitated brings with it the serious prospect that the person they care for will be at serious risk.

### **In summary**

***Carers Allowance should reflect honest commercial payments for the services that they provide.***

***The basic structure to assess the different levels of Care that is needed - already exists; Carers should receive increased levels of Allowance for providing higher levels of Care.***

***If there was an approach to funding Carers at a level relative to what they contribute there may be a significant incentive for people to take on the Caring role and reduce the need for institutional care.***

***I believe these arguments put to the Productivity Commission on Paid Maternity leave by Professor Barbara Pocock would apply equally to at least those Carers who are caring for patients with high care needs.***

***The Carer Payment could be totally scrapped and what Allowance all Carers get should be related only to what they do, and related in an honest manner to market rates.***

***There should be immediate acknowledging that being a Carer and that the Carer Payment and Allowance is payment for work for the purposes of the Superannuation Co-contribution regulations.***

***The Government should make compulsory contributions to the superannuation funds of carers.***

***There is a need for flexible access and support for financial counselling for Carers.***

***The current level of financial and other support for Carers seriously undermines Family Values and discourages people from becoming Carers.***

***There is a need for better financial and other support for Carers and this should bring with it more access to necessary social activities and improve the role of the Carer and their quality of life.***

***The provision that 'if the person is out of your care for a set number of hours' then you do not receive any support - should be eliminated.***

***It should be first established that a person requires care, and then if a team of people share in providing that care then the financial support should be able to be apportioned between them based possibly on the number of hours of care required and/or the care provided by each Carer.***

***Carers' need for flexibility in employment should be recognized and may need to be more rigorously supported by anti-discrimination provisions.***

***Developing and maintaining Job and Carer Skills should be recognized as part of a long-term life plan, and the Carer should be encouraged with financial and***

***respite support to participate in continuing education while they are still Carers.***

***Carers need more financial support, better socialization and continuing education. Society should 'Care for the Carers' and Carers should be able to realize they are affirmed and supported by society.***

***Individualized counseling and support services as well as access to support services that are flexible should be available to all Carers.***

***Cumulative Long service leave and sick leave should be added to Carer's entitlements so that when they are no longer Carers that financial support will continue when they are better able to take that leave.***

***Services in rural and other areas should be surveyed to identify shortfalls in support services and steps taken to provide this support.***

***Carers need better access to health care, and should have respite and support services so they can access the health care when it is provided.***

***There is a need for better and continuing education for Carers tailored to the changing tasks and roles they take on, as well as access to aids and equipment to assist in their tasks. There needs to be proactive access to services such as Occupational Therapy and other resources to equip Carers to perform the changing tasks they encounter.***

John

Wednesday 18 Jun 2008

**Appendix**, a few selected headlines

**Australia facing aged care time bomb**

Article from: **Herald Sun**

By Ben

June 12, 2008 03:50am

**AUSTRALIA is facing an aged care time bomb, with more nursing home residents needing expensive high-care places for longer. ....**

ABC News

**Dementia forcing older Aussies in care for longer: study**

Posted Thu Jun 12, 2008 6:11am AEST

Updated Thu Jun 12, 2008 9:31am AEST

The report shows 70 per cent of permanent aged care residents needed a high level of care.

A new Australian Institute of Health and Welfare report has found older people are spending longer in aged care facilities and need a higher level of attention, partly because so many of them have dementia. ....

etc etc etc etc etc etc for many other days of news