

A.O.C. 8/7/08

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

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.

I am submitting this report to the inquiry as I believe I have important and significant personal and professional insight into the impact of caring. Firstly, I am the personal Carer of a war veteran. Secondly, I am the President of a State welfare organisation, and Vice-President of a National welfare organisation, which represents more than 300,000 individuals.

**1. The role and contribution of carer's in society and how this should be recognised.**

I believe that carers are undervalued, grossly under supported, and probably misunderstood by society and most certainly by the three tiers of government. As noted by the Access Economic Report 2006 carer's provide approximately 1.2 billion hours of voluntary care, which if purchased from formal care providers would cost the Australian taxpayer over \$30 billion per year. The report also estimates that at any one time there are 2.6 million carer's looking after relatives, family or friends who are incapacitated due to disability, mental illness, chronic medical conditions or age. Furthermore, national government policy has seen mass de-institutionalization across Australian, placing even more emphasis and pressure upon voluntary carer's in the community. Although the philosophy of de-institutionalization may be sound and seeks to keep those who cannot care for themselves living in and connected to their local community, they have failed to support the carer. It is clear that through this policy the government has made significant savings and has failed to pass on the funds previously associated with state and institutional caring to appropriate community supports to assist carer's. Quite simply, it appears that money has disappeared back into government coffers, leaving already stretched general community services to cope with increasing demand from undervalued carer's. As

noted it is clear that the role of the carer is critical to ensure that individuals are kept within their community and family networks. It is now time that the government channels significant funds into assisting the carer. This includes:

Access to timely regular on going respite. A carer should not have to wait for extensive periods of time to access regular respite in order to allow them to continue to cope with the on going demands of caring. If a carer is not adequately supported, they may be forced to relinquish care to the government at significantly more cost than respite would ever be. Respite care should be no less than 8 weeks per year. For example paid professionals such as police in high stress work are entitled to 8 weeks per year and they work on a shift work basis. A carer works under significant emotional, personal and physical stress 24/7 and as such should be afforded a minimum of 8 weeks respite in total per year. This should not include any respite required if the carer themselves requires any health related respite i.e. hospitalization, recuperation. Emergency short term care is vital so that the carers may attend medical appointments and maintain their own health. The World Health Organisation recognizes that carers have a fundamental human right to have a life apart from caring and access to regular breaks from caring.

Immediate access to general and specialist services, including equipment. This may include any medical or allied health services such as access to physiotherapists, dieticians, psychologists and speech therapist. As the government is already aware services such as these are stretched to the limit and waiting lists are long and extensive. In order for a carer to continue caring and to appropriately support the person for whom they are caring timely quick access is required and that this access should not be time limited or session numbers limited. These services also need to be appropriately covered by Medicare or government funding. In addition, this should also include greater access to funds and services which provide specialized equipment for those with physical or medical disabilities. This would save the carer financial burdens, long waiting lists and impacts on their health and wellbeing with the access and use of specialist equipment.

The promotion of positive health and wellbeing for carer's. This could be done through the development of target policy and guidelines to assist service providers

across the community. In addition, the education and marketing of carers contribution and to target and assist carers to improve their health and wellbeing.

Carers awareness training and understanding amongst professionals. It is unfortunate but a fact that carers and their role are sometimes minimised by uninformed professionals. For example when dealing with a doctor who believes that anyone with a disability can learn to look after themselves, although this is not always the case. Therefore the doctor will not complete necessary forms for the carer's to receive any government funded assistance. Thus, there is a need for workers in the health and social care sector to have access to carer awareness training.

Reduction in government eligibility duplication and waiting times. Currently all tiers of government and government services fail to communicate appropriately and thus the carers is left filling out and completing numerous paperwork for each individual service or support, often repeating the same information over and over. For example a war veteran will complete the necessary forms and proof for eligibility for the Department of Veterans Affairs (DVA) and then when attending Centrelink for assistance, they are required to go through the same lengthy and burdensome process again to establish the same disability and therefore eligibility. All that is required is for Centrelink to recognise what DVA has already assessed i.e. a tick box for \*Special Rate recipients (VEA) and \*EDA. Recipients (VEA) Aside from the frustration that doctors are expressing to carer's that they are tired of completing government copious amounts of paperwork, carers themselves are being increasingly stressed and fatigued through the process. Furthermore, a benefit for the government would be the cost saving from the streamlining of processes and the reduction of public servant work hours and administrations involved. The duplication of red tape between Centrelink and the DVA could be greatly reduced or even eliminated.

## **2. Barriers to the social and economic participation for carer's, with particular focus on helping carer's to find and/or retain employment.**

A majority of Carers are socially and often geographically isolated, detached from the general community. Families fragment due to marriage breakdown and financial stress among other things often resulting in one carer shouldering the entire burden.

Caring for someone requires a high level of focus, time and commitment which is often difficult to balance with the needs of other members of the carer's family such as children who may suffer needlessly. The carer also can experience high levels of anxiety and guilt as a result.

The economic cost to society (government) of low level care is about \$45,000 per annum as noted by the Veteran Affairs Network and DVA. The economic cost to a family can be much greater with loss of opportunity, employment, superannuation, capital gain (if self employed), insurance etc. Carers experience difficulties in attempting to pursue careers when they enter a caring role. In order to support carers to find and retain employment the following areas need to be addressed:

Access to increased financial assistance. In the instance of veterans and their carers they may be able to receive either the carer's payment or a welfare service pension, however neither rate enables a livable standard, thus the carer and veteran are essentially on borderline poverty. Economically the carers role is greatly devalued, especially in light of the cost of a funded caring service. In addition, the carer should be able to access part time work to pursue their career without fear of their government financial assistance being reduced. That the financial burden is lessened on the carer by increased Government financial assistance direct to the carer.

Share care respite. For a carer to return to the work in some capacity, they need a form of shared care respite. Share care may be provided in either in home or day program/activity environment.

Flexible work arrangements. For example a carer could work from home, with appropriate equipment provided by the employer i.e. lap top, printer, internet, phone. This way the carer could perhaps work on articles for newspapers or organisation leaflets, they could also do a varied range of project work or even graph design. The options for stay at home work are endless with today's technology. It is a matter of government providing employers with education about this option and sufficient support to assist employers to employ carers under such a scheme. It is not a new idea, as many industry and organisations are allowing full time or part time workers this opportunity, so why not the carer if they desire. This also assists the care to

reduce isolation and provide contact and mental stimulation from others which would contribute to their sense of wellbeing and worth.

**3. The practical measures required to better support carer's, including key priorities and actions.**

Please refer to dot point items listed under sections 1 and 2.

**4. Strategies to assist carer's to access opportunities and choices, including strategies to increase the capacity for carer's to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.**

Definition, value and focus of disabilities. There are many carers who care for someone with a cognitive disability or mental illness, however, the majority of government forms and paperwork only refer to physical conditions. Cognitive and mental conditions are just as debilitating as a physical one, yet seem to be rated less important or of less interest to organisations or government bodies. This makes the process very difficult and complex when attempting to meet eligibility criteria for organisations such as Centrelink. Please refer to the Claim for Carers Allowance and/or Carer Payment application form from Centrelink as a specific example. All government bodies and funded services need to review and change their paperwork to accurately reflect the nature of all disabilities both mental and physical as equally important. In addition, caring organisations, such as those I represent should be invited to be part of a work force or to contribute through other means the definition and value of disabilities i.e. a veteran with Post Traumatic Stress Disorder and Acrophobia and alcoholism are just as debilitating as someone with (say) Fredrick's Ataxia – they just have different needs.

The recognition of carers as equal and expert partners in the delivery of care. This could be done as part of the carer awareness training focused at professionals in the health and social care sector and through support government policy.

Training support for new carers in their caring role.

Access to case management services. Case management services should be made available for carers to access at times of need. A time limited case management service could assist with carers identifying areas of needs and services to meet these needs. This would include planning for the short and long term with clear goals to be achieved i.e. accessing employment and or long term care for the person they looking after.

Transitioning from current carer to past carer. Past carers needs to be recognised and their contribution valued. That is support them with service or professionals or voluntary groups and bodies with dealing with letting go of a caring role and redefining who they are, dealing with the health and wellbeing which may have been effected as a result of their previous caring role and educating them and transitioning them from specialist services to general community services over time.

**In conclusion,** I thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to the opportunity to review any recommendations made to improve the life for carers in Australia. I am available at your convenience to discuss or expand upon any of the information contained within this document. I may be contacted on

Without prejudice,



Shirley

President, Partners of Veterans Association of Australia, Victoria Branch Inc  
Vice-President, Partners of Veterans Association of Australia Inc

\*VEA - Veterans Entitlements Act 1986

\*EDA – Extreme Disablement Adjustment

\*Special Rate – S.24 VEA