

Submission No. 655

(Inq into better support for carers)

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The Partners of Veterans Association of Australia Inc.

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Patron: Mrs Lynne Cosgrove

3rd July 2008

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,

The Partners of Veterans Association of Australia Inc. (P.V.A.) welcomes the opportunity to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

P.V.A. is a National welfare organisation with five state branches, and was established to be the national voice and focus for the welfare, support and special interests of the more than 300,000 individuals who are partners of war veterans. In representing partners of veterans, our organisation has significant insight into the impact of the caring role; many of our members are the carer of not only their disabled war veteran, but also in many instances for ill/disabled children and elderly frail parents.

1. The role and contribution of carers in society and how this should be recognised.

In the words of Committee Chair Annette Ellis, "Carers are often the hidden and unsung heroes who tirelessly look after family members and friends who cannot look after themselves". P.V.A. acknowledges and supports these comments and believes that carers are not only undervalued, but also grossly under supported, probably misunderstood by society and most certainly by the three tiers of government. There is insufficient acknowledgement and/or support for the sacrifices carers make in caring for their loved ones.

As noted by the Access Economic Report 2006 carers 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 Australia, placing even more emphasis and pressure upon voluntary carers 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 carers. 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 carers.

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.

Moreover, the quality of care received by the person being cared for is a result of the quality of life, health and well-being of the carer; and P.V.A. maintains that adequate regular respite without financial penalty is needed to prevent stress problems and burnout for carers.

Immediate access to general and specialist services, including equipment.

This may include any medical or allied health services such as access to physiotherapists, dieticians, dentists, 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.

Being a primary carer is a very taxing role and many carers have given up careers to take on a full-time carer role, resulting in lack of opportunity to amass superannuation or even adequate savings; and in many cases, carers may be living below the poverty level and cannot afford private medical insurance which would generally give them quicker access to medical services.

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 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 mental 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 carers.

The maintenance of carers' health is considered to be a significant public health issue, as it determines their capacity to provide care for people in their own homes who otherwise may have to rely upon the publicly funded institutional health care (Battam 2004)

The promotion of positive health and wellbeing for carers 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.

Carer 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 carers 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.

P.V.A. believes that all tiers of government and government services fail to communicate appropriately and this leads to carers being left to fill out and complete copious amounts of 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 repeat the same lengthy and burdensome process to establish the same disability and therefore eligibility.

P.V.A. recommends that all that is required is for Centrelink to recognise what DVA has already assessed; i.e. include a tick box for *Special Rate recipients (VEA) and *EDA. Recipients (VEA) on relevant forms. As well as the frustration that doctors are expressing to carers that they are tired of completing copious amounts of government 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.

Recognition of Carers of Disabled Veterans by Department of Veterans Affairs (DVA)

In its Election 07 Policy Document - *'Labor's Plan for Veterans' Affairs'* one of the six goals foreshadowed by a Rudd government was *"To care for families of veterans, in recognition that it is not just veterans themselves who make personal sacrifices to defend our country"*

P.V.A. has long maintained that the Department which is responsible for the disabled war veteran should also be responsible for the carer of the veteran and in recognition of the sacrifices made by partners and families of veterans, DVA should acknowledge the role and contribution of carers of disabled war veterans and provide adequate funding to support these carers.

2. Barriers to the social and economic participation for carers, with particular focus on helping carers 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. Being the primary carer 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 carers 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 carer role is greatly devalued, especially in light of the cost of a funded caring service. In addition, if the carer is able to access part-time or casual work, they should be able to pursue their career without fear of their government financial assistance being reduced. Thus 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 carers, including key priorities and actions.

Please refer to dot point items listed under sections 1 and 2 and the following:

Clearer guidelines for Centrelink staff assessing Applications for Carer Allowance

P.V.A. suggests that Centrelink staff who assess Applications for Carer allowance may need more training and indeed should have clearer guidelines to assist them in approving/refusing Carer Allowance Applications. In making representations to Centerlink on behalf of members who have been refused Carer Allowance, P.V.A. has noted the following reasons/problems:-

- Carer of disabled veteran informed by Centerlink staff that Post Traumatic Stress Disorder (PTSD) is not a permanent disability and moreover is curable;
- An 'Acute Event' is only an occurrence such as car accident, heart attack etc;
- An 'Acute Event' must have occurred in the last 6 months;
- Carers Allowance is not payable for psychiatric disability;
- Elderly carer of veteran refused Carer Allowance on medical grounds - her 80 year old veteran is DVA assessed as Totally & Permanently Incapacitated; he is asthmatic, has had 2 hip replacements and shoulder reconstruction, arthritis, uses a walker and an oxygen bottle;
- Elderly carer refused Carer Allowance - 76 year old veteran recently had heart operation and operation on leg - carer told of community services and a 'relaxation' cassette;
- Carer of terminally ill veteran was reviewed by Centrelink and had her Carer Allowance cut off. Veteran husband dies several weeks after.
- Some Doctors have refused to complete the Carer Allowance Application form for a veteran suffering from mental illness, because the doctors state that the veteran is not in a wheelchair or severely physically impaired.

Continuation of Carer Bonus Payments

P.V.A. suggests that continuation of annual bonus payments to Carers is a practical measure which supports carers.

Feedback from PVA members indicates that many carers see the bonus payments as appreciation and recognition by the government for the sacrifices they make in their on-going caring role. To cease giving the bonus payments and increase the fortnightly Carer payments/allowances would be counter productive as many carers often use the bonus to purchase much needed items such as a replacement fridge or washing machine or indeed at times repairs to a motor vehicle.

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

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. Literature suggests that the "up and down" aspects of mental illness are more detrimental to carers' health than those who have a higher physical workload, but on a consistent level. This makes the process very difficult and complex when attempting to meet eligibility criteria for government departments 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 the P.V.A., 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 is just as debilitated as someone with (say) Fredrick's Ataxia – they just have different needs.

Centrelink Review of Eligibility for Carer Allowance

The Carer Allowance Application form includes the questions: *Is this condition permanent?* and also: *Is this condition likely to improve?* If the answers to these questions indicate that the condition is permanent and unlikely to improve, P.V.A. suggests that any two yearly review of eligibility for the Carer Allowance should take the form of a phone review only.

Moreover, In the case of carers of war veterans who are assessed by DVA to be a Totally & Permanently Incapacitated Veteran or an Extremely Disabled veteran, P.V.A. maintains that the review of eligibility for receipt of Carer Allowances should be under the same conditions as the carer of a person with a permanent physical disability such as paraplegia. Neither condition will improve and a phone review should be sufficient.

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 are looking after.

Transitioning from current carer to past carer.

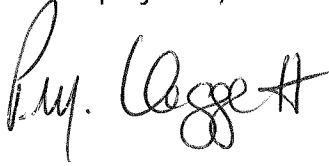
Past carers needs to be recognised and their contribution valued. That is support them with services, or professionals or voluntary groups and bodies, in dealing with letting go of a caring role and redefining who they are; dealing with the health and wellbeing which may have been affected as a result 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 the views of P.V.A. into consideration as part of the Committee's Inquiry and 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 on information contained within this submission and I may be contacted as follows:-

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Without prejudice,



Pat Cleggett
Secretary
The Partners of Veterans Assoc of Aust Inc.

- *VEA - Veterans Entitlements Act 1986
- *EDA – Extreme Disablement Adjustment
- *Special Rate – S.24 VEA