

Huntington's Victoria Carer's Group

**Submission to the Parliamentary Inquiry into Better support for Carers
July 2008**

Huntington's Victoria Carer's group (see Appendix 1) holds regular support group meetings to provide peer support for people caring for someone affected by Huntington's disease. At a recent meeting we discussed the following questions in relation to the Terms of Reference for this inquiry.

Terms of Reference 1: Role and contribution of carers in society and how this should be recognised

What is caring for a person with HD like and what impact does it have on your family?

- Caring is a huge financial burden
- Time caring for the person with HD means time taken away from your own family. Other family members are "abandoned" or "deprived of attention" Worry that caring for HD person means neglecting your own children.
- Carer's health suffers as they have less time to concentrate on self and wellbeing.
- Loss of relationships and friends and social isolation
- Increased stress levels and greater responsibility; "have to live their lives for them", "burden of decision making"
- Peace-keeper in HD family
- No acknowledgement of role of carer (financially, socially or emotionally).

Recommendations

- 1. Government should provide an appropriate wage for carers.**

Terms of Reference 2: Barriers to social and economic participation of carers

What support and assistance do carers need to stay in the workforce?

- Caring for person with HD is a 24 hr/day job due to the complexity and unpredictability of the disease.
- Not possible for a sole carer to remain in workforce

If you are working, what makes it possible to mix your caring role or what do you need to stay in your job or run your business?

- Complete respite care
- Another full-time carer

Have you had to reduce your working hours due to your caring responsibilities?

- Carer can only work if other people are involved in the care (eg father and daughter sharing care of)

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- The stress with working and caring compromises the quality and quantity of work. Need a very understanding employer
- Most carers need less responsibility in work roles – may have to change careers and acquire new skills

Recommendations

- 2. Provide incentives for employers to enable them to provide flexible working options for carers.**
- 3. Provide more support to carers for respite and personal care attendants to enable carers to work outside the home.**

What impact will your caring role have on your retirement savings?

- Carers have no retirement savings. This is due to loss of employment income, costs of caring, & accommodation bonds for nursing homes. Carers often access super at a young age to survive.
- Carers are often young with many years of life ahead and lose financially – superannuation, employment, accommodation costs, assets sold for bonds.
- Carers consider they would be financially better off on a pension than carer's allowance.
- Carers can't afford or have time off for holidays or travel. (Example of family that sold holiday home to pay for mother's accommodation bond. Family is still caring for son and can no longer afford holidays.)

Recommendations

- 4. Government should introduce a compensable system for people with acquired brain injuries or degenerative neurological diseases similar to the Transport Accident Scheme which operates in Victoria. This could be funded from a small levy paid by all income earners and would provide the funds to prevent families from having to use their superannuation funds to survive these conditions.**

Does the current level of financial support for carers from Centrelink adequately meet the needs of families?

- No. Carers have to "weave their way through the welfare system".
- The system makes it very difficult to access correct information – Centrelink staff don't provide consistent responses, and explanations are often too complex (not in layman's terms).
- Don't have time to try and navigate the complexities of the system. Mentally exhausting. Carers tend to give up due to complexities in accessing resources

Recommendations

- 5. Establish a regular contact team of Centrelink staff who can be accessed for HD clients irrespective of geographical location. This would be based on the current Centrelink teams that liaise with hospitals.**

Terms of Reference 3: Practical measures required to better support carers, including key priorities for action.

Are there more or different welfare arrangements needed to better reflect the reality of caring for a person with HD?

- Need community Centrelink system to work solely in the HD community

What barriers do you face in being a carer?

- Accessing adequate resources/information and support.
- Carers are extremely vulnerable. They are often forced to accept sub-standard services eg young male sent to shower elderly woman
- Social barriers- difficult to leave home.
- Lack of continuity of allied health staff for care and support
- System barriers
- Access – particularly for carers that can't drive. Visiting specialists or a loved one in a facility is difficult
- Lack of understanding by health and justice systems of the symptoms and needs of people with HD eg Crisis Assessment Team staff won't come in a crisis, police arrest/charge people with HD.

What practical things would assist you to overcome these?

- Education about HD for health professionals (eg general practitioners, personal care attendants)
- Education about HD for police in responding to situations when involved with HD
- Appropriate referrals to neurologists/psychiatrists and allied health professionals
- General education/awareness/support in the community
- Greater in home support/ services especially as those with HD deteriorate.

Recommendations

- 6. Expand eligibility for the taxi voucher system to include transport for carers who are visiting people in facilities.**

Terms of Reference 4: Strategies to assist carers to access the same range of opportunities and choices as the wider community

How do you see the future of yourself and your family?

- Dim and dark, drained, depleted.
- Hard to predict the future as progression of the disease is so variable.
- Worried about future generations, our children

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What are your expectations of Government assistance/programs in the future?

- Optimistic that Government will listen to carer's feelings of hopelessness and respond appropriately
- Put carers at the top of the Government's priority list not the bottom.
- Recognise that carers save the Government money.
- Build more appropriate facilities, in particular more homes for young people.

What are the important things you need from the health, education and community care system?

- Help
- Understanding
- Emotional support
- More research and a cure for HD
- Flexible health and welfare systems

Recommendations

- 7. Simplify the system so that people do not have to fill out forms and keep giving details to every different agency.**
- 8. Establish consistency in decision making about eligibility and support benefits.**
- 9. Improve the training of Personal Care Attendants to that the standard of service improves.**
- 10. Expand the definition of 'carer' to recognise that carers continue to play a significant role in caring for the person with HD after they are placed in a residential facility (eg. visits, weekends at home, outings and also making major decisions and taking responsibility etc) without financial or other support. With this expansion would come associated funding support to allow the carer to continue in their role.**

Appendix 1

Members of the Huntington's Victoria Carer's Group care for one or more members of their family who are affected by Huntington's Disease (HD). The members of the group who contributed to this submission are:

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