

## Better Support for Carers Inquiry Notes

Huntington's Victoria August 2008

**1. Establish a compensable system based on the Victorian Transport Accident Scheme, which would cover all people who develop an acquired brain injury or develop a degenerative neurological disease. This could be funded from a small levy on all income earners.**

- ❖ Idea for a small levy to be paid by all income earners to fund a national scheme. James Macready-Bryan Foundation is lobbying for this.
- ❖ To be discussed in further detail by MS Australia.

**2. Pay carers a wage in recognition of their economic contribution to the burden of care.**

- ❖ This recommendation was raised by our carers as a major issue
- ❖ MS Australia and Carers Victoria will expand on this area in relation to superannuation and flexible working arrangements
- ❖ This is linked with the compensable system and also with expansion of eligibility for benefits ie if there is a compensable system in place, carers will not need to be paid from other sources

**3. Expand and simplify the definition of 'carer' to recognize that carers continue to play a significant role in caring for a person after they have gone into supported accommodation. Use this expanded definition to increase eligibility for supports to allow the carer to continue in their role. See also 8.**

- ❖ Most people in facilities will still have a carer who carries significant responsibility regarding their well being and this should be recognized
- ❖ People need support to be able to visit their loved ones when in accommodation eg travel costs to reach accommodation can be prohibitive for some people so introduction of travel allowance would help
- ❖ Example of child losing counselling support when parent went into care

- ❖ Eg Sue losing carers allowance due to hours over incorrect number of days
- 4. Create high quality respite options which provide meaningful activities for people with neurological diseases, beyond the current system, which has been developed for people with intellectual disabilities.**
- ❖ We have quoted the figures in our submission on how much carers of people with HD reduce their spending on entertainment, holidays, restaurants and personal care ie being a carer is a barrier to recreation and self care
  - ❖ Extremely difficult to get appropriate respite because people with HD are generally young (between 35 and 55). Since the introduction of the COAG Young People in Nursing Homes Initiative many barriers have developed to getting people under 65 into a nursing home. Previously getting an ACAS assessment involved making a phone call, now, many regions will not consider people under 50, while other regions require complex paperwork and have huge delays.
  - ❖ We applaud the COAG initiative and appreciate that Victoria is making progress towards building accommodation for young people, however we are still many years away from having enough accommodation to fill the needs of the population and we need a workable transition plan in the meantime, that recognizes that for some young people, nursing home level care is the best current option.
  - ❖ People with HD are becoming progressively brain damaged, and some can exhibit aggressive, impulsive and violent behaviors, and can create safety and duty of care issues for the staff and other residents in general respite
  - ❖ People with HD respond best to an appropriately structured and supportive environment. In care settings that confront, restrict and punish, the person often responds by becoming increasingly resistant and unmanageable.
  - ❖ These people need specialized care with highly skilled staff who can manage challenging behaviors eg in a Behavioral Disorder Unit such as at the Royal Talbot Centre. This centre has 30 beds and was established as a rehabilitation centre for people with ABI, but currently we have 4 people with HD in there.

- ❖ These people will display violent behaviours for a short period (3 – 4 years) until their deterioration prevents them from posing a risk to themselves or others and they can be appropriately housed in other types of accommodation.
  - ❖ Currently we have enough clients to fill another 10 bed unit such as this one on a permanent basis, and that is only for Huntington's Disease. There are other younger onset dementias that would show similar presentations in some individuals.
  - ❖ There are psychogeriatric facilities for people over 65, what we need urgently are similar facilities for people with younger onset dementias.
  - ❖ A number of respite beds in a unit such as this would make a huge difference for families struggling to care for their loved one in the family home and would be an important step towards permanent care.
  - ❖ Regional locations would also support carers in their caring role.
- 5. Improve access to respite services, including in-home, overnight and out of home services.**
- ❖ Increased funding for emergency respite so it can be made available more readily.
- 6. Provide incentives for employers to enable them to provide flexible working arrangements for carers.**
- ❖ MS Australia to speak further about flexible arrangements.
- 7. Develop the Personal Care Attendant workforce, including development of a career structure and minimum standards, to ensure adequate supply of high quality support workers.**
- ❖ There is a crisis looming with this workforce because with the introduction of Individual Support Packages more and more people require PCA supports
  - ❖ Need to develop a career structure that could lead onto further qualifications in the care sector eg allied health
  - ❖ Very low pay leads to high turnover rates as people find better paying jobs

- ❖ Poor support for training is an issue. We will train PCAs but they are not paid for their time by their employers, so do not attend our free training. Training support incentives could help with this.

**8. Simplify eligibility criteria and processes for provision of carer's allowances and specialized equipment. .**

- ❖ Details as per 3;
- ❖ Equipment ie specialized HD wheelchairs

**9. 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.**

- ❖ There are many issues with incorrect information being given from Centrelink staff to clients, in addition to extremely distressing incidents of poor service provision. The one issue that makes our clients cry is when they talk about Centrelink.
- ❖ We are aware of 2 Centrelink Community Teams that provide support and information to Melbourne's inner city hospitals.
- ❖ These teams are experts in issues relating to benefits and allowances for people who are hospitalized
- ❖ Do not provide outreach support
- ❖ They are first point of contact for staff needing information, advice on forms to be filled in, direction in which office to send forms etc.
- ❖ We propose that Centrelink trains a small number of staff to be experts in issues relating to people with neurological conditions, and their carers. There would be a direct line for expert advice, without going through a generic call centre.
- ❖ In this instance 'neurological conditions' refers to Huntington's disease, multiple sclerosis, motor neuron disease, muscular dystrophy, Alzheimer's, stroke, ABI, Parkinson's.
- ❖ These community officers would provide education, information and support for Centrelink workers who have clients who are affected by or care for people with neurological conditions. They would also provide information and support for case workers working with clients affected by neurological conditions and their carers.

- ❖ They would not provide direct services to clients, and clients would not be able to contact them. Rather, they would provide a consultancy service to community and hospital based staff and be the expert link between Centrelink and case workers. If a particular Centrelink office was getting complaints about knowledge or service, they would provide on site training to improve knowledge and avoid future problems.

**10. Establishment of a service to provide ongoing practical, consistent and accurate information for carers to help them address legal and financial issues.**

- ❖ With all degenerative neurological conditions, you are dealing with young people planning for nursing home care and all of the legal and financial implications for their families eg power of attorney and guardianship issues, superannuation, benefit entitlements, tax implications of certain benefits and pensions
- ❖ This is the single most important issue identified by our carers
- ❖ Case study: Two years ago Mrs D received a donation from the Starlight Foundation for her son. She has not filled out a tax return since as she is so worried that she may owe the tax office money because of the donation.
- ❖ There is no current supplier of reliable or consistent information in this area. Many organisations give fragmented advice but that makes it extremely difficult for carers to get information or even understand the range of information they require. They may need to ring OPA, Centrelink, State Trustees and the ATO as well as see a financial counselor based in their local council.
- ❖ State trustees will complete a tax return but don't provide any financial counseling
- ❖ The Office of the Public Advocate can give advice on guardianship and administration issues but don't give any financial advice
- ❖ Centrelink can provide information on an individuals' income and assets, but don't provide assistance with tax matters or legal issues
- ❖ Neighbourhood Houses and Carers Victoria can only refer people to external financial counseling services

- ❖ Financial Counseling Victoria provides free financial counseling, but only operates in the southern region and primarily works with people experiencing consumer debt.
- ❖ We propose that government should fund a service that would provide high quality, individualized, timely, expert, accessible and free or low cost financial services. This could be through expansion of an existing body or the creation of an entirely new organisation.

**11. Establish a 24 hour carers' support line. This would provide an emotional support for people who are isolated, but could also provide access to emergency services when necessary.**

- ❖ Current support line services are fragmented and inconsistent in the scope of service provision
- ❖ The Carers' Resource Advisory line and Carers Victoria provide information, personal support and access to counseling but only operate during weekdays and business hours.
- ❖ The Commonwealth Respite Centre is a 24 hour service but only provides assistance with locating respite services.
- ❖ Our carers report the urgent need for a 24 hour service that can provide emergency support in a crisis but can also provide information and support on carers' issues.
- ❖ We propose an expansion and rationalization of current services to provide one national carers support line.

**12. Establish a national database for patients, that includes relevant information which could be accessed by services beyond the medical service, eg Centrelink, police.**

- ❖ We are aware that the National Health and Hospital Reform Commission and Health and Welfare Institute are working towards a national medical records database and that the Australian Government is committed to eHealth and is facilitating the transition of paper-based clinical record keeping to electronic means for better information exchange.
- ❖ We realize that this is a huge undertaking, but the benefits for carers – not having to repeat their story countless times, consistency of information, medical information recorded not the carer trying to remember – would be enormous.

- ❖ We strongly support the development of eHealth and we propose its expansion to include limited access for police and Centrelink staff so that carers and families do not have to tell their stories from the beginning each time they deal with a new agency.
- ❖ This would help agencies deal with situations such as intervention orders, or diagnoses.
- ❖ Eg if a person with HD gets arrested for drunkenness the police can verify their HD status on this system.

**13. Provide suitable accommodation for people with younger onset dementias, who are exhibiting significant behavioural issues. This facility should be secure and staffed by experts in dealing with behavioural presentations. A 10 bed facility would cater for the degree of incidence of younger onset dementias in Victoria.**

- ❖ People with Huntington's disease are often difficult to place in accommodation due to the complexity of the illness. The person may have cognitive, psychiatric, behavioural, emotional and physical manifestations.
- ❖ Because so many different areas of functioning may be affected, people with behavioural presentations may not easily fit into one system of care, so often end up being placed in inappropriate facilities, such as acute mental health services or prison.
- ❖ Because the age of onset may be in the person's 30's or 40's, they are not suitable for aged care either, but may end up in a nursing home or a psycho geriatric facility.
- ❖ Most hostels and SRS's are not set up to manage behavioural difficulties / challenging behaviour.
- ❖ The multifaceted and complex nature of HD means that people have needs that often fall between the mental health, acute health, disability and residential care systems.
- ❖ People with HD respond best to an appropriately structured and supportive environment. In care settings that confront, restrict and punish, the person often responds by becoming increasingly resistant and unmanageable.

- ❖ People with HD tend to respond very well when living in facilities that have strict boundaries, firm limit setting and a predictable routine i.e. Royal Talbot BDU, however the BDU is a 30 bed facility which provides neurobehavioural rehabilitation and expect thru-put, so are at times hesitant to admit a person with HD due to the length of admission (3 to 4 years).
- ❖ Excessive demand on existing neurological and specialist accommodation services means there are long waiting lists and services have a limited capacity to meet current needs.
- ❖ An increase in specialized residential care is needed so that people with HD and their families have confidence that their their loved ones will be safe and can maintain the best possible quality of life.
- ❖ This will also reduce the risk to the community and to residents of other accommodation who are currently exposed to these behaviors.