

Huntington's Victoria Submission

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Submission

Parliamentary Inquiry Into Better Support For Carers July 2008

Introduction

Huntington's Victoria conducted 3 focus groups with carers to discuss the issues relating to this inquiry. This submission begins with a brief background on Huntington's Disease followed by discussion points and recommendations presented in relation to three of the terms of reference of the inquiry.

Background

Huntington's Disease (HD) is a degenerative brain disease

Huntington's Disease is a disease of the brain that is passed down through the family line. It is a progressive, degenerative, genetic disease, which means that the symptoms gradually worsen over time. It affects people's ability to think, move and talk, and can also cause changes in the individual's personality. The illness usually begins between the ages of 35 and 45 and lasts for 15 – 20 years. It is invariably fatal. If a parent has HD, each child has a 50% chance of inheriting the defective gene and also developing the disease.

HD can affect several family members at the same time

A family's capacity to provide ongoing support to each affected member is often strained because of the length of the disease, and the fact that several generations may be affected at the same time. Carers of someone with HD may go on to develop the disease themselves, as well as having siblings with the disease. For example, a woman may have a husband who has HD, one or more children who have HD, as well as grandchildren who are at risk of developing the disease. Currently 400 people in Victoria have HD, with a further 2,500 family members at risk of developing the disease.

People with HD require complex care

The complexity of HD with its cognitive, affective, psychiatric and motor aspects as well as its genetic and degenerative aspects means that people with HD require a high and ongoing level of support and care as the disease progresses. Although the presentation of the disease differs with every individual, it is common in the early stages of the disease for people to become clumsy, have difficulty in walking, become irritable, have short term memory loss, and to develop twitching in their muscles. As the disease progresses the people with HD may lose the ability to walk and communicate, develop psychiatric symptoms, develop dementia and lose the ability to swallow.

Discussion points and recommendations

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

"You no longer have something to look forward to – we're at the age where our children have grown up and there is nothing"

"You have to work hard at giving yourself a life"

"If you do something, it is usually on your own"

"You have to do everything"

"I need help as a carer. I find it stressful dealing with the constancy of it all. I have this need to keep my husband content, when he is content I feel OK, when he's not I feel extremely stressed"

"I need a break, but you don't feel you can take a break unless exactly what you provide can be replicated"

"The case managers are good with the bigger picture things – it's the smaller things that you don't feel come under the episode of crisis!"

"You can no longer relate to your colleagues or friends – you become a different person and end up isolated"

A recent study on the economic impact of neurological diseases on families found that patients have consistently higher levels of social support satisfaction than their carers¹.

Sally has recently made the difficult decision to place her husband John in a nursing home. She travels for 45 minutes each way to see him. Each weekend he comes home to visit the family. Since he left home, Sally and her son no longer qualify as 'carers'. Her son was receiving counselling through a carers agency, but this suddenly stopped when his father went into care. Sally has had to take on full time work as she cannot afford the petrol costs to visit John. She no longer receives a carers support payment even though John spends the threshold amount of hours at home. She has been told that this is because the hours John spends at home are not spread over the correct number of days.

Recommendations

- 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.**
- 2. Pay carers a wage in recognition of their economic contribution to the burden of care.**
- 3. Expand and simplify the definition of 'carer' to recognise 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.**

2: Barriers to social and economic participation of carers

A diagnosis of Huntington's Disease reduces the average family income by \$44,174, and increases their expenses by \$24,544, making families nearly \$70,000 worse off per year¹.

78% of HD carers reduced their spending on entertainment, 76% on holidays and restaurant meals, 60% on hairdresser visits and 52% reduced their spending on food due to economic pressures¹.

"He's always stuck at home. It would be good to regularly get out of the house"

"You don't have a life – you live from peg feed to peg feed"

"Friends want to visit but they don't know how to make the interaction work. What they used to talk about is no longer relevant"

"It's the same with other diseases, people don't know how to handle it"

"You gradually lose your friends."

"I don't have the time or energy or money to socialize"

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"If I want to do something on my own I have to book a respite service, which can be expensive or not available when I need it."

"I feel guilty if I ask for respite"

"Practical support needs to be available when its time to go into respite or long term care

"It's hard to get respite for that period before the person is moved into residential care – you have to negotiate it with the HD person but they are not listening to you. Usually it only happens when you are desperate and end up in hospital"

"You have to be in hospital to get help"

Recommendations

- 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.**
- 5. Improve access to respite services, including in home, overnight and out of home services.**
- 6. Provide incentives for employers to enable them to provide flexible working arrangements for carers.**
- 7. Develop the Professional Care Attendant workforce, including development of a career structure and minimum standards, to ensure adequate supply of high quality support workers.**
- 8. Simplify eligibility criteria and processes for provision of carers allowances and specialised equipment.**

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

The single most important issue reported by our carers is the complexity of dealing with Centrelink and the Australian Taxation Office. They experience inconsistency, poor service and delayed or inaccurate payments.

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"It affects my brain, I'm constantly put down. After a while you start to think it is your fault"

"The hurt! Everyone says don't take it to heart but you can't help it"

"There are challenges to my integrity, especially in public"

"He was telling social security I was stealing from him. He loses something and he blames me"

"The loss of my self esteem as a carer"

"The people there have never dealt with the disease. They don't understand why your husband can't be brought in to be interviewed or the fact if he was there he would leave in the middle of the interview"

"I was only eligible for a carer allowance – to get that I had enormous difficulties"

"I dealt with Centrelink through a social worker. Everything that is on Centrelink triggers something else – there is always paperwork every time your situation changes. I'm not asking for much!"

"Centrelink couldn't define what a partner was – she is my wife but they wanted to know if I visit her. I now have a financial counsellor deal with them"

"I need someone to go to the organisations that provided funding and fight for me"

Our families report that there are an overwhelming number of financial and legal decisions that need to be addressed. These include tax implications, power of attorney, guardianship issues, health insurance, life insurance and mortgages. Support needs to be in place to help people make these key life decisions. While interventions such as financial counselling would be of great benefit, it is also important to focus on preventative and educational strategies in order for families to be able to prepare for financial and legal changes. Information needs to be presented in a simple, user-friendly format, with plenty of options for the carer to seek further information and clarification.

"I had to leave the house, take the kids out of school and arrange for a Court Order. It took the police 2.5 days to serve the court order and I ended up in the Magistrates Court three times to stop him re-entering the house"

"You lose a lot financially as prior to diagnosis he was managing the big picture finances. When men are involved there is often huge financial loss before the diagnosis – they can only see the short term. My husband kept selling assets after he lost his job, now we struggle financially"

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"Huntington's Victoria can't help until the person is diagnosed and this is the hard part"

"I need somebody to help out with guidance, direction and decision making – my role has now changed. I'm the captain of the ship for everything"

"The enduring power of attorney is the most important document you will ever have, you can't do anything without it"

"Assistance with things such as wills and enduring powers of attorney. I have never dealt with a solicitor before and it was completely daunting filling out the paperwork given the stress I was under. I want someone to sit with me."

"The ATO and other organisations won't speak with you unless you have the enduring power of attorney"

"Help in transferring everything over to my name (authority for paying bills)"

Huntington's Carers have stated that they often struggle to find someone to talk to who understands what they are going through. They express sadness that they have become disengaged with their social group, either because they are so busy caring for their family members that they no longer have the time or energy to see friends, or because friends have drifted away since the diagnosis.

Young carers require additional supports due to the complex issues they face. As well as trying to attend school and finding and fitting into their own social groups, they are often assisting in the care of an ill parent. In the case of HD, not only are children dealing with the physical, emotional and financial strains and demands of helping care for a parent with HD, they are also living with the knowledge that they face a 50% chance of inheriting the disease.

Other carers face serious risk of harm due to the behavioural presentations of some HD patients. Carers reported finding resistance from services such as the CAT team to attend if there were violent outbursts during the night.

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Many people with HD do not fit into the service system. Carers report that their family members are refused access to psychiatric facilities because HD is not defined as a psychiatric illness, even though people can exhibit severe psychiatric symptoms such as violent or aggressive behaviour, psychosis and paranoia. This leads to CAT teams refusing to attend emergencies, leaving the carer at significant risk, or psychiatric facilities refusing to admit patients, leaving them with no suitable accommodation which can manage their behaviours. People with this presentation of HD can often move between facilities for years, before their condition deteriorates to the point where they no longer present a risk to themselves or others.

"It would be great to be allocated a person who you can ring up and say, please help me deal with this"

"I need help, in the middle of the night, when he is violent and I am at risk and no one will come to help me"

"I need help with things that my husband has always done and I can't physically do. You should be able to go through Council but it takes forever and each time the questions are endless"

"The police don't know what HD is"

"I'm so tired of telling the same story over and over, and having to answer the same never-ending questions"

"I find a massage is great for me. I got two for the year from Carers Victoria. Finally they gave it to me after I rang the Mayor and I got someone from Carers Victoria to actually come and see me. It's the extent you have to go to"

"Help us find and fund equipment. At times this is cost prohibited"

"I need someone to come and mow the lawns and help with the house work and tasks my husband used to do"

Recommendations

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.

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- 10. Establishment of a service to provide ongoing practical, consistent and accurate information for carers to help them address legal and financial issues.**
- 11. Establish a 24-hour Carers support line. This would provide emotional support for people who are isolated, but could also provide access to emergency services when necessary.**
- 12. Establish a national database for patients, that includes relevant information which could be accessed by services beyond the medical service, eg Centrelink**
- 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.**

Reference

1. Economic Impact of Neurological Illness on Wellbeing McCabe, Firth, O'Connor and Roberts 2007.
Some data from this study was presented at the National Huntington's Conference in 2006, other data have been published in the *Journal of Sex & Marital Therapy*, 34:115-132, 2008

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