



**Australian Huntington's Disease Association (NSW)
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The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600

Dear Sir/Madam

Re: Inquiry into Aged Care

Please find attached a submission from Australian Huntington's Disease Association (NSW) Inc.

If you require any further information please do not hesitate to contact me.

Yours sincerely

Robyn Kapp OAM
Executive Officer

Senate Community Affairs References Committee

Inquiry into Aged Care

Young People with Huntington Disease and Residential Aged Care Facilities

Australian Huntington's Disease Association (NSW) Inc

Introduction

Unfortunately the only option for many young people with advanced stage Huntington Disease (HD) is placement in nursing home facilities for the frail aged. This means young people with HD, whose average age is approximately 50, are living with people whose average age is 80. The Australian Huntington's Disease Association (NSW) strongly believes that this is not an appropriate solution for this group of people.

Because of the nature of HD and its progression they require nursing home standard of care. However they also need services that enhance their quality of life such as diversional therapy, including outings, social interaction with their peers etc. Young people with HD who are living in nursing homes do not experience the same rights and standards as young people with HD living in Huntington Lodge at Lottie Stewart Hospital (LSH) at Dundas, NSW. At LSH there is staff experienced in HD including nursing staff, physiotherapist, occupational therapist, dietician and speech pathologist. There is also regular input from a neurologist and psychiatrist.

There are at least 6,000 people, covering a wide range of disabilities and illnesses and under 65, living in aged care facilities across Australia – over 1,000 of these are under 50. The fact that in many cases no other alternatives exist for people with high support needs means that nursing homes have become a first, not a last option for these people. However even gaining admission to a nursing home has become increasingly difficult for people aged under 65.

The tragedy of this situation is that each young person is isolated from their peers, from the community and from the opportunity for appropriate care, environment and resources.

The Aged Care Act 1997 specifies that younger people with disabilities will be accepted into nursing home care on compassionate grounds and where there is no alternative. Young people with disabilities living in nursing homes do not experience the same rights and standards recognised in the Disability Services Act 1987. This is because funding for the frail aged is provided by the Commonwealth Government and the responsibility for the provision of care for young people with disability, including those with Huntington Disease lies with the various State Governments.

In NSW, however there is the anomaly at Lottie Stewart Hospital where there are 30 CADE (Confused and Demented Elderly) beds which are funded by the NSW State Government. It is not possible for young people with HD to access these beds for the same reasons outlined above.

Huntington Disease (HD)

- Huntington Disease (HD) is an inherited, degenerative brain disorder which affects individuals of either sex.
- HD is degenerative: symptoms gradually worsen as the disease progresses. At present there is a number of treatments to improve the symptoms but as yet there is no cure.
- Symptoms usually begin to appear between 35 and 45 years of age, often after the gene has already been passed on to a new generation.
- HD is most commonly characterised by involuntary movement and lack of co-ordination. People with HD have often been falsely accused of drunkenness.
- As the disease progresses the jerking and twisting movements are more likely to increase. Swallowing and speech difficulties also develop. There can also be weight loss and a need for greater caloric intake
- People with HD usually experience irritability, depression and mood swings; a reduced ability to plan, organise, process complex information and learn new material; and some lack of insight
- HD is slowly progressive over an average of 15-20 years
- Each child of an affected parent has a 50% chance of inheriting or escaping the defective gene. If they inherit the gene for HD they will eventually begin to show symptoms.
- After 10 to 15 years from the onset of symptoms most people with HD will require nursing home standard of long term care. However there are those that require such care earlier than this. They include:
 - ◆ those with a lack of family support due to breakdowns in family relationships.
 - ◆ those with younger age of onset (teens to 20's) and therefore have faster progression resulting in earlier need for nursing home standard accommodation.
 - ◆ those with 'at risk' behaviours and cognitive dysfunction.

Residential Care for People with Huntington Disease in NSW and the ACT

In the past people with HD were often placed in psychiatric hospitals when they could no longer be cared for at home. However since the formation of support organisations such as the Australian Huntington's Disease Association (NSW) and the establishment of the NSW Huntington Disease Service (Westmead Hospital, Lottie Stewart Hospital) there is now a better understanding of HD, particularly the psychiatric aspects, among health care professionals. Consequently few people with HD require care in psychiatric facilities.

In the ACT there are no specialised services for people with HD and their families.

Today the options for long term residential care are aged care facilities, that is:

- Hostels (low level care residential facilities) which are funded by the Commonwealth Government. Hostels are suitable for people who are still mobile, that may require assistance with personal hygiene, dressing, laundry, shopping, meal preparation or supervision with medication.
- Nursing homes (high level care residential facilities) which are also funded by the Commonwealth Government) and provide 24 hour nursing care for residents.

In NSW and the ACT there is currently a desperate need for appropriate long-term "nursing home standard" care for people with HD who are under the age of 65. In Huntington Lodge, the specialised HD unit at Lottie Stewart Hospital, the age range is 33 to 54 years, (12 are aged under 50 and 3 are between 50 and 54). As this unit only has 15 long-term beds many people (under the age of 65) have to be placed in aged care nursing homes.

In 2002 there were 105 (75 of whom were under 65) people known to the NSW Huntington Disease Service in residential care. (NB this figure does not include all cases known to the Hunter HD Service in Newcastle).

Of this 105

- 90 were in nursing homes
- 14 were in hostels
- 1 was in a psychiatric hospital

The number of people with HD aged under 50 and in residential care was 31.

Of this 31

- 23 were in nursing homes (13 at LSH)
- 8 were in hostels

The number of people with HD aged between 50 and 60 and in residential care was 33.

Of this 33

- 27 were in nursing homes (3 at LSH)
- 3 were in hostels
- 1 was in a psychiatric hospital

- 2 were in care but the level not known.

It is understood that figures for 2004 are similar.

The process for any person entering an aged care facility, either hostel or nursing home, includes an assessment by the Aged Care Assessment Team (ACAT) and the issuing of an Aged Care Client Record (ACCR). However obtaining an ACCR (formerly a 2624 certificate) and an appropriate placement in an aged care facility for a person with HD and under the age of 65 is extremely difficult.

The experience of the social workers attached to the NSW Huntington Disease Service is that ACATs refuse to undertake assessments because the people are young (ie under the age of 65) and have not been trialled with other services.

Additionally, people with HD are often not referred to the NSW Huntington Disease Service until they well into the illness and it is then too late to trial them at home with these other services.

Nursing homes are also refusing to take people with HD, the reasons being:

- their difficult behaviour and they are disruptive to older, frail patients
- their physical symptoms
- they require extra food, butter, cream, sustagen, etc
- they require extra time for feeding
- they often require special beds or chairs such as the fallout bed which costs approximately \$2,000.
- the nursing homes don't get enough funding for people with HD because the cognitive impairment does not rate high on the Resident Classification Scale.
- nursing staff are distressed by having to care for such young patients.

Huntington Lodge at Lottie Stewart Hospital often experiences the following:

- emergency respite is clogged because there is no respite in other places
- because generic nursing homes are not accepting people with HD, there are no vacancies at LSH and there is a back-up of people waiting to be accepted into Huntington Lodge.

Conclusion

It is clearly apparent that:

- Aged care facilities are inappropriate for young people with advanced HD who are no longer able to live independently.
- There is an urgent need for specific accommodation facilities that provide a "nursing home" level of care for young people with advanced HD together with regular medical and health assessments as well as age appropriate services including social activities.
- That Commonwealth and State governments take a collaborative and proactive approach regarding these vital issues.

Appendix 1

Case History

The following is an example of a typical case the Social Workers have experienced. Other examples have been documented and are available. Names and details have been changed to protect confidentiality.

Case History 4:

- Mark is 36 years old, single and has never worked.
- He lived alone in private rental in Sydney but was evicted for inability to look after flat and erratic rent payment.
- He is now living with a sibling in provincial town and is on Disability Support Pension. He was originally was on Newstart.
- Sibling brought him to the HD at Westmead Hospital where he was diagnosed clinically and on MRI.
- Mark has dementia and psychotic thinking, he has been seen by a psychiatrist and prescribed anti-psychotic drug which he will not take.
- He requires prompting and supervision with washing, dressing, meal preparation, cleaning and money management and his siblings believe he needs residential care.
- He was admitted to Lottie Stewart Hospital for respite/assessment but he absconded after two days as Mark does not believe he has HD.
- He often goes missing for days, travelling by train to Central Railway Station and not coming home until the early hours of the morning or he may go missing for days.

Action

- Mental Health Team initially would not get involved as HD is not a mental illness “within the meaning of the Act”. They visited once after a call from the HD psychiatrist.
- ACAT refused to take referral for 2624 – low level hostel assessment because of his age (36) but have accepted referral for Boarding House assessment. He is on a waiting list for this but there are no licensed boarding houses close to his siblings.
- He is on a waiting list for Co-options to assist his sibling.
- He is on a waiting list for a local case manager.
- He is on a waiting list for public housing.
- His siblings are adamant that he is not capable of living alone.
- His reverse day/night sleep pattern and habit of roaming for days will mean he will not be able to be contained at home for services to come but a 2624 cannot be approved unless services have been tried.
- Mark was referred to the NSW HD Service after his eviction and he was already well into his illness.

APPENDIX 2

Current Services for People with Huntington Disease in NSW

The NSW Huntington Disease Service

Western Sydney Area Health Service provides services at Westmead Hospital and Lottie Stewart Hospital. These include:

- Weekly Outpatient Clinic for diagnosis, ongoing supervision of treatment and counselling.
- Huntington Lodge – specialised residential unit for people with HD
- Outreach Service which includes social work, occupational therapy, speech pathology, diversional therapy, physiotherapy, nursing and dietetics. This service also provides in-service and education sessions to nursing homes at no charge.
- Outreach Clubs for people with HD held twice monthly at Lottie Stewart Hospital.
- Social groups for people with HD and relatives held periodically in Wollongong, the Central Coast and Blue Mountains

Other services include:

- HD predictive testing and counselling program at the Children's Hospital at Westmead.
- Predictive testing through the clinical genetics services in Newcastle, Sydney Children's Hospital at Randwick, Liverpool Hospital. Outreach genetics clinics are also available in rural areas and the ACT.
- Hunter HD Service which is based in Newcastle and provides predictive testing and social work support.

Australian Huntington's Disease Association (NSW) Inc.

The Association was established in 1975 and

- Distributes a bi-monthly newsletter.
- Provides information and telephone counselling.
- Funds research.
- Conducts two fortnightly Lunch Clubs for people with HD.
- Organises two holiday camps for people with HD each year.
- Holds seminars and family support meetings.
- Produces and distributes a wide range of printed materials on HD.
- Manages a group home for people with HD in Newcastle.
- Funds and manages the Rural Outreach Service for southern NSW and the ACT.
- Has established an education/information resource centre.
- Provides in-service education programs.
- Conducts community awareness programs.
- Advocates on behalf of families to government and non-government bodies.

References:

“Creating a Pathway from Aged Care to Appropriate Care”, Report on the National Summit for Young People in Nursing Homes.
2nd May 2002.

“A Caregiver’s Handbook for Advanced Stage Huntington Disease”, Author and Editor Jim Pollard, published by Huntington Society of Canada 1999 and reprinted in Australia by the Australian Huntington’s Disease Association (NSW) Inc.

NSW Huntington Disease Service, Westmead Hospital and Lottie Stewart Hospital.