Australian Huntington's Disease Association (National)
21 Chatham Road, West Ryde NSW 2114 Australia
PO Box 178, West Ryde NSW 1685 Australia
Telephone: +61 2 9874 9777
Facsimile: +61 2 9874 9177
E-mail: robynk@ahdansw.asn.au

30th July 2004

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 (National).
This submission has been prepared in co-operation with the following organisations.
Australian Huntington's Disease Association (Qld) Inc.
Australian Huntington's Disease Association (NSW) Inc.
Australian Huntington Disease Association (Vic) Inc.
Australian Huntington's Disease Association (Tas) Inc.
Australian Huntington's Disease Association (SA & NT) Inc.
Australian Huntington Disease Association (Inc) WA

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

Yours sincerely

Robyn Kapp OAM
Treasurer, AHDA (National)

Senate Community Affairs References Committee

Inquiry into Aged Care

Young People with Huntington Disease and Residential Aged Care Facilities

Australian Huntington's Disease Association (National)

Throughout Australia people with Huntington Disease (HD) are frequently accommodated in residential aged care facilities (nursing homes and hostels). It is acknowledged that many such facilities accommodating people with HD have acquired significant experience and expertise in managing people with HD over time, and indeed there are facilities that have more than one resident with HD. Experienced staff from either the HD Associations or state government funded HD Services work closely with residential aged care facilities in an effort to support and maintain placements. Education sessions are offered and frequently assistance in the development of management strategies for the particular person with HD is provided. Facilities are encouraged to request further education sessions or consultations, and to maintain regular phone contact to assist in monitoring difficult situations.

However, despite the fact that many people with HD are successfully managed in mainstream residential care facilities, there still exist a number of difficulties in this area. A range of issues and difficulties has been identified and are summarised as follows:

- The difficulties in obtaining ACAT assessments for people under 65 years
- The difficulty in getting nursing homes to take people under 65 years even if there is an ACAT assessment
- The unsuitability of nursing homes for frail aged for people with HD under 65 years.

Huntington Disease (HD)

- Huntington Disease (HD) is an inherited, degenerative brain disorder which affects individuals of either sex.
- Symptoms usually begin to appear between 35 and 45 years of age but sometimes may be seen in those younger or older, including teenagers and the elderly.
- HD is most commonly characterised by
    - ♦ involuntary movement and lack of co-ordination. People with HD have often been falsely accused of drunkenness.
    - ♦ swallowing and speech difficulties
    - ♦ irritability, depression and mood swings
    - ♦ reduced ability to plan, organise, process complex information and learn new material
    - ♦ some lack of insight
    - ♦ weight loss and a need for greater caloric intake
- 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 began to show symptoms.

- At present there is a number of treatments to improve the symptoms but as yet there is no cure. 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.

See Appendix 1 for an in depth description of advanced stage HD.

Huntington Disease Associations

Huntington Disease Associations exist in each of the six states and they provide a wide range of specialist services to individuals, families and carers. All state associations produce regular newsletters which have up to date information on research, services and activities.

Other services provided can include:

- Information / education
- Counselling
- Assessment and referral
- Day and holiday respite
- Carer support
- Advocacy

Residential Care for People with Huntington Disease

Residential facilities for people with HD include aged care residential facilities (nursing homes and hostels), boarding houses, supported residential services (SRS) and HD specific facilities. HD specific facilities are located at Lottie Stewart Hospital (NSW), Arthur Preston Residential Services (Victoria), Brightwater (WA).

Boarding houses and SRS accommodation are not considered to be appropriate long-term residential options for people with HD as support provided is extremely limited. Furthermore, the facilities are unable to cater for people with challenging behaviour. The cost of SRS facilities, which are privately run, is prohibitive to clients who are almost invariably financially disadvantaged. Paying high rents also reduces the clients' capacity to manage the additional requirements they frequently have as a result of HD, for example, additional food and food supplements and transport costs to access regular medical and allied health appointments. Boarding house and SRS accommodation are often used as a "last resort", usually whilst awaiting placement in the aged care system where no other option, such as living at home with family, exists. Frequently placement in a residential aged care facility is precipitated by a crisis at the boarding house or SRS due to the inability of the facility to manage the person. However, people residing in boarding house and SRS accommodation may not be appropriate in terms of their care needs for aged care residential facilities, highlighting the need for an "intermediate" stage of accommodation.

Throughout Australia 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.

See Appendix 2 for examples of Case Histories.

Clients requiring placement in the aged care system are usually accommodated eventually; however the process which includes obtaining an ACAT assessment; the issuing of an ACCR and finding appropriate accommodation can be difficult and tedious.

See Appendix 2 for examples of Case Histories.

It is the experience of social workers and welfare workers that ACATs often refuse to undertake assessments because the people are young (ie under the age of 65) and have not been trialled with other services.

Clients are frequently placed in accommodation which happens to be available rather than that which caters to their specific needs. In some cases clients may be accommodated in the acute hospital system whilst awaiting placement in the aged care system.

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.

Other difficulties encountered by clients placed in residential aged care facilities include, for example:

- Restricted access to regular assessment in areas such as neuropsychology and allied health services etc. Such regular assessments can be critical in developing appropriate management strategies for people living in facilities and whose needs change over time and whose care plans need to be revised on a regular basis to accommodate their changing needs.
- Residents of aged care facilities are unable to easily access the specialist HD clinics, mainly due to the difficulties in transporting patients to these clinics.
- Clients with HD placed in residential aged care facilities frequently miss out on appropriate social support, as many of the activities in these facilities are aimed at frail older people and have little interest for younger people with HD. Furthermore, people with HD usually need one on one support to engage in activities, and a lack of resources in facilities means that such support is very difficult if not impossible to provide.
- Restricted access to specialist equipment such as beds, chairs, shower equipment and communication aids. Residents are precluded from applying for assistance under the PADP scheme for such aids because they live in residential facilities.

Many people with HD are successfully managed at home for lengthy periods of time with the support of a range of services. Such services include home care, meals on wheels, and respite care, both in home and out of home, for carers. Many clients are well supported by packages such as Community Options, Linkages or Community Care Packages which can frequently prolong care at home and delay admission to residential care.

However, several difficulties arise when attempting to link clients into packages. For example, a Community Care Package, being funded by the Commonwealth Government, requires assessment by the Aged Care Assessment Team, and this is frequently a difficult process as ACAT guidelines are such that services are reluctant to assess, let alone provide appropriate paperwork for, younger people with HD. Agencies which provide packages also have criteria for assessing and wait listing people for packages, and social/welfare workers frequently report difficulties in accessing packages. Even referrals to such basic HACC services as home care and meals on wheels can be difficult – such services experience heavy demand and impose criteria for assistance, frequently those carrying out assessments are limited in their experience of HD and fail to understand the implications of the range of symptoms which may be affecting a person with HD. For example, a client may have mild movement disorder but significant difficulties in capacity to plan and organise. Assistance with home care, shopping and meals in such a situation can be very helpful, but assessment officers frequently find it difficult to understand their situation.

Conclusion

As a result of the nature and progression of HD, most people in the later stages require a level of care which at present is mainly provided throughout Australia for the majority of people with HD by mainstream residential aged care facilities. However placing young people with HD into aged care facilities is an inappropriate solution in the long term, although it is currently the only alternative that many people with HD have when they are no longer able to live independently. Even then they are faced with extreme difficulties primarily because ACAT teams refuse to assess them - because they are under the age of 65 and are therefore the responsibility of the State Government under the State and Territory Disability Agreement. If they are fortunate enough to be assessed, nursing homes often refuse to take them because of their age, the complexity of their support needs and the challenging behaviour associated with the progression of the disease.

To raise the standard of care and the quality of life of people affected by HD we would implore the Commonwealth, State and Territory governments to take a collaborative and proactive approach to decision making on this issue. As we see it, the only appropriate course of action in the short term would be for all governments to consider developing more specialised nursing home care for people with HD (based on the models currently operating in Victoria, NSW and WA) and issuing a joint directive to ACAT teams that people with Huntington Disease under the age of 65 must be assessed for nursing home placement.

Robyn Kapp OAM
Treasurer
AHDA(National)
29th July 2004

Appendix 1

Advanced Stage Huntington Disease

The following description has been adapted from *"A Caregiver's Handbook for Advanced-Stage Huntington Disease"* by Jim Pollard and reprinted in Australia by the Australian Huntington's Disease Association (NSW) Inc.

Huntington disease is made up of three disorders - a movement disorder, a cognitive disorder, and an emotional disorder. Some people with HD have a very severe movement disorder but very little cognitive impairment. Others have profound cognitive changes but few movement problems. The emotional disorder is often depression, which comes and goes throughout the course of the disease.

Every person experiences the beginning of HD in a unique way. Some first notice small subtle movements. Others find themselves becoming forgetful, and still others become depressed. Every person experiences the progression of HD in a unique way, too. For example, one might have a rapid deterioration in cognitive function and less decline in the control of movements. Another person may have rapidly increasing difficulty with movements, but no significant change in cognitive functioning during the same period of time. Therefore, no two people with HD will present the same caregiving challenges. But in the most advanced stages, all symptoms converge in a predictable manner.

Movement Changes
By the time a person with adult-onset HD requires long term nursing home care the movement disorder is usually quite apparent. The symptoms have progressed to a point where all muscles are affected and walking takes on a "dance-like" quality. People often try to camouflage and control the movements. As the involuntary movements, often referred to as chorea, become more exaggerated, what was once "dance-like" now looks "drunk-like". Speech becomes affected as words are slurred. As balance deteriorates, falling occurs more often, and the affected person becomes unable to walk safely without assistance. Beds may need padded side rails to prevent the patient from bruising himself or falling out.

At the same time, it becomes increasingly difficult for the person with HD to speak and be understood. Nearly all people develop a swallowing disorder, need a special diet, and need assistance eating. In addition, most residents eventually need adapted beds and chairs to accommodate their severe involuntary movements, impaired balance, and changes in posture.

Cognitive Changes
The cognitive disorder is less apparent than the movement disorder, but more disabling in many ways. Long before the need for nursing home care, people with HD struggle with subtle changes that affect work and family. Their ability to organize and plan slowly begins to erode, and routine tasks, previously performed effortlessly, become more complicated to complete. As cognitive function continues to deteriorate, people with HD may become quite inflexible and resistant to suggestions

and change. As a result long-term relationships often breakdown. People with HD usually are unaware of these changes will vigorously deny their existence.

Their thinking is slower, initiating action is more difficult, learning new things is not as easy as it once was, and judgement is impaired. They may become unreasonably demanding of family, friends, and caregivers.

Emotional Changes

The emotional disorder is primarily made up of depression that runs throughout the course of HD. Having seen a parent suffer with HD, knowing that only further decline and dependence is at hand, and recognizing all that one has already "lost" to HD, are justified reasons why the person with HD may have a reactive depression.

Idiopathic depression, one that is not triggered by life's events, is also common. Some people with HD who are depressed appear irritable or angry. Some deny depression because they lack insight. Others are unconsciously protecting their feelings. Even in the most advanced stages of HD, people who show classic signs of depression can respond well to medication. Suicide in HD occurs more often than in the general population. Depression paired with a lack of impulse control makes suicide a major risk for patients in all stages of the disease.

Appendix 2

The following case studies have been compiled illustrate the main points of concern. Names and details have been changed to protect confidentiality.

Case History 1:

Difficulties in obtaining ACAT assessments for people under 65 years

- Robert is a 36-year-old man who is living in a caravan park.
- He was diagnosed with HD two years ago.
- He is well supported by his mother who lives nearby but he is struggling to maintain his independence while his capacity to care for himself deteriorates.
- Initial attempts were made to explore the provision of support services but his present accommodation, in a caravan park, made this very difficult.
- It was also considered that his accommodation, with shared and inconvenient facilities, placed Robert, whose cognitive skills are deteriorating, at considerable risk.
- A referral was made to the local ACAT service.
- The ACAT advised that they were unable to carry out an assessment unless a letter from the Department of Human Services Intake Service (Victoria), stating that there were no appropriate services available to this person, had been obtained.
- After a delay of some 4 weeks such a letter was obtained and submitted to the ACAT, who subsequently advised that they still were unable to assess due to Roberts' age which according to their guidelines made him unsuitable for residential care they were unable to carry out an assessment.

NB In Victoria a statewide meeting was held in May 2004 which was attended by ACAT and Department of Human Services (DHS) intake staff to address the concerns about increased workload resulting from the ACAT requirement for a letter from DHS prior to accepting a referral for a younger person. At this meeting it was agreed that the new protocol would be that ACAS would not require a letter from DHS intake before accepting a referral.

In contacts with ACAT staff it has sometimes been necessary to remind staff about the new protocol; however the easing of the requirement that a DHS letter be obtained has made ACAS referrals much easier, and generally the ACAS staff involve the referring agency in the assessment.

Case History 2:

Difficulty in getting nursing homes to take people under 65 years even if ACAT has provided assessment.

- Sam is a 45-year-old man who had been living in rural Victoria.
- Sam has a triple diagnosis of intellectual disability, schizophrenia and HD, and his behaviour has very been difficult to manage over a period of time.
- Initially Sam's care needs were more related to his intellectual disability and schizophrenia.

- However, over time his HD symptoms became more prominent and his resulting increase in care needs meant that he was considered appropriate for nursing home placement.
- Whilst an ACAT assessment and relevant paperwork for admission to residential care was obtained, it proved to be very difficult to find a nursing home in his local region which was willing to take him.
- Frequently facilities which have had limited or indeed no experience of caring for someone with HD are reluctant to take on someone such as Sam whose care needs are high and whose behavioural presentation can be very difficult to manage.
- Eventually Sam was placed in a facility in Melbourne which currently has 3 people with HD and has had experience over a number of years in caring for people with HD.

Case History 3:

Unsuitability of nursing homes for frail aged for people with HD under the age of 65 years.

- Shauna is 36-year-old woman who had been living interstate but returned to Victoria to live with her family, as her care needs increased.
- Despite efforts by her family to manage her at home her care needs were such that she required the level of care only available in a nursing home.
- Shauna also presents with significant behavioural problems, which have impacted greatly on other residents.
- This is exacerbated by the fact that the activities provided at the facility don't meet her needs, causing escalation in her difficult behaviour.

Case History 4:

- Anna aged 35 to 40 years
- Affected at least seven years
- Cognitive decline – primary presentation feature
- Mother of 4 young children (youngest child preschool age)
- Family reside in rural remote area – limited access to other mainstream support services
- Various admissions to Mental health services until diagnosis and subsequent stabilisation of medication for depression
- Requires a range of in home care and support – limited availability an average of 10 hours per week in home assistance (includes worker travelling, accompanied visits to GP or related appointments)

Impact of physical and cognitive decline for Anna

- Loss of independence
- Loss of skills and abilities and quality of life
- Loss of family life

Unable to provide mothering role,

- Partner – cares for children, works full-time and is primary carer for Anna
- Anna needs prompting and supervision with personal hygiene, medication, unable to manage household or financial affairs, or assist with any household tasks

Impact on family
Unable to parent appropriately

- Decline in family status (middle class now unemployed)
- As a consequence negative impact on children's schooling, discipline issues, reactive behaviour, episodes of family conflict, – appropriate authorities involved
- Safety issues in home (previous potentially dangerous accidents related to Anna and children)
- Severe financial difficulties – loss of income, potential loss of partner's income.
- Change from private ownership to public housing waiting list

Outcome for Anna

- Declined assessment by ACAT (age related and does not meet criteria for permanent care (Cognitive disability not recognised as criteria for assessment as 'high need'). *Aged care facilities not appropriate for younger people*
- Assessed by ACAT for respite only - limited availability of respite beds (only available at certain nursing homes) and fees apply for all facilities
- Would accept permanent residency at Eskleigh, however, subject to waiting list, resources both human and financial. However, a consequence of accepting if placement became available is that Anna would be isolated from children. Distance would prevent regular visits.
- Remains at home (unable to function in parental, partner or family roles, totally dependent)

Outcome for family

- Continued financial, social deprivation and disadvantage
- Family believe appropriate residential care required – not available in Tasmania

Case History 5:

- Barry aged 50 to 55 years
- Affected at least 10 years – 'positive at risk' status known for 15 years
- Early physical decline – speech and mobility – less cognitive – challenging behaviours (long term issue for family and carers)
- Two significant past relationships limited and to no contact with children until early symptomatic stage – no contact in later stage
- Relocated to isolated rural area from central city area - short time prior to decline
- Unable to support self placed in aged facility rural area – referred out
- Resident supported accommodation - challenging behaviour cited referred acute care mental health
- Discharged acute level continued residency 6 months
- Refused assessment by ACAT - Several reviews requested
- Referred district hospital 5 months– returned to acute care – staffing issues cited
- Acute care awaiting transfer mental health system or acceptance in any alternative care

Impact HD of physical cognitive decline on Barry

- Unable to sustain immediate or extended family relationship
- Loss of ability to express choice, opinion, independence
- Unable to feed, clothe or attend to personal hygiene when living alone in remote area

- Confined to, aged care facility 40 to 45 years of age – no family support - isolation – subsequently, established in supported accommodation no family support
- Removed (challenging behaviour cited) refused re-entry – loss of peer group personal space and possessions

Impact of HD on family

- Grief, loss of family life – generational effect
- Loss of contact
- Social, financial and education disadvantage

Outcome for Barry

- Occupies bed in acute care mainstream health and mental health system – limited social contact clinical environment, limited divisional therapy
- Homeless or awaiting alternative

Acknowledgements:

Australian Huntington's Disease Association (NSW) Inc
Australian Huntington's Disease Association (Vic) Inc
Australian Huntington's Disease Association (Qld) Inc
Australian Huntington's Disease Association (Tas) Inc
Australian Huntington's Disease Association Inc (WA)
Australian Huntington's Disease Association (SA & NT) Inc

References:

"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.