# HUNTINGTON'S DISEASE AND DISABILITY CARE

## *Submission to the Disability Royal Commission*

Endorsed by

**Huntington's NSW & ACT**
**Huntington's QLD**
**Huntington's SA**
**Huntington's TAS**
**Huntington's WA**

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# HUNTINGTON'S DISEASE

## IMPACT

Huntington's disease (HD) is a hereditary neurological disease that causes selective brain cell death which results in progressive and relentless physical, cognitive and emotional deterioration. The dominant feature of HD is chorea, an uncontrollable twisting and jerking of the limbs, alongside progressive dementia for some. Those with adult-onset HD usually develop symptoms between the ages of 35 and 50, although onset can be later in life or even earlier in the case of juvenile-onset.

The end result for a person with HD is they are in many cases still very aware but are unable to walk, speak, or eat normally and they are totally dependant for all areas of care 24/7 for 15 to 25 years.

HD is terminal. People living with HD, after experiencing years of high dependency disability, will die between 15 to 25 years after symptoms first appear.

HD not only impacts on a person, it impacts on families, relatives, generations and communities. It cruelly robs a person of the ability to think and move normally. and often renders their behaviour unpredictable and antisocial. There is no cure and every person with it is affected in a different way and over a different time frame.

The genetic nature of HD means that each child born of a parent with HD has a 50% chance of inheriting the disease themselves. Testing is available from the age of 18, however, due to the absence of effective treatment, only approximately 15% of those at risk will choose to be tested. Although there is no cure or effective treatment, there are research teams actively seeking alternative therapies, as well as professional carers (including exercise and occupational therapy) looking to develop a better quality of life.

## PREVALENCE

A study in NSW in 2018 found the prevalence of people with manifest HD (HD with noticeable symptoms) to be 7.5 per 100,000 of the population.[1] Australia's current population of 25.6 million people would translate this prevalence into approximately 1920 people with HD[2]. Tasmania has reported a considerably higher prevalence of 12.1 per 100,000[3].

However, we recognise that the NSW study is now considered conservative. Several international studies have identified the prevalence of up to 10 - 12 per 100,000[4][5]. Finally, anecdotal evidence from some of our state associations points to an even higher prevalence as new families become known to them, indicating a potential prevalence more than 3,000.

[1] McCusker, Elizabeth A., Reynolds F. Casse, Shanthi J. Graham, David B. Williams and Ross Lazarus, *Prevalence of Huntington disease in New South Wales in 1996*. Medical Journal of Australia, 173 (August 2000), 187-190. This study by McCusker et. al. is considered the best study on prevalence in Australia. A follow-up study by Dr Clement Loy (current Director of the Westmead HD Service) to be published later this year is expected to find an incidence of 7.5 per 100,000. We note that data from Tasmania indicates a much higher prevalence there of 12.1 per 100,000 (due to a founder effect), which should be taken into account when developing future public policy.

[2] https://www.abs.gov.au/AUSSTATS/abs@.nsf/Web+Pages/Population+Clock?opendocument&ref=HPKI

[3] Pridmore SA.: The prevalence of Huntington's disease in Tasmania. Med J Aust. 1990;153(3):133-134

[4] Rawlins MD, Wexler NS, Wexler AR, Tabrizi SJ, Douglas I, Evans SJW, Smeeth L: The Prevalence of Huntington's Disease. Neuroepidemiology 2016; 46:144-153. doi: 10.1159/000443738

5 Spinney L.: Uncovering the true prevalence of Huntington's disease, The Lancet June 9:8: 760-1 Aug 2010 https://doi.org/10.1016/S1474-4422(10)70160-5

# SUMMARY OF SUBMISSION

Huntington's disease (HD) is a hereditary neurological disease that causes profound and relentless progressive physical, cognitive and emotional deterioration, leading to significant disability and premature death. HD usually presents in mid to late adulthood but can emerge earlier in life, sometimes as juvenile-onset. At present, no cure and no effective treatments exist for HD. Eventually, most people with HD require residential care. For more than 75% of people with HD in Australia, as the disease and subsequent disability progresses, the only option has been residential aged care. Of these people, it is our understanding that the majority will enter residential care before they turn 65, even though current residents are over 65, thus meeting the categorisation of young persons in aged care.

This submission primarily relates to the challenge of providing care to Australians with disabilities caused by HD, a) living in community care and in receipt of NDIS services and b) living in residential aged care, particularly younger people (<65 years) with disabilities caused by HD.

Our over-arching **recommendation** is that people with HD needing residential care should receive this in NDIS-funded, specialist environments with properly trained staff. Aged care is almost never the right solution.

This submission provides personal stories and case studies of the experiences of younger Australians living with HD in the residential age care system (page 11).

## COMMUNITY CARE

Community care for people with HD is now predominately funded through the NDIS. This care needs to be tailored to the specific needs of a person living with a terminal and progressive neurological disease. Our experience is that these conditions are frequently not meet, seemingly because the NDIS is philosophically geared toward increasing community participation and registrants' employability by *"… investing in people early to build their capacity to help them pursue their goals and aspirations resulting in greater outcomes later in life"*. [6] Key objects of the NDIS Act are to *"…support the independence and social and economic participation of people with disability…"* and *"…promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community"*.[7] However, these values do not apply to people living with a progressive disabling illness. Therefore, people with HD and their carers are continually fighting to obtain appropriate care and support, as the nature of the disease prevents them from fitting into this dominant paradigm.

The care required for people with HD throughout their disease progression is well understood by families, and specialised support carers, with the assistance of a few committed clinicians and allied health professionals.

**Recommendation**

Mainstream NDIS providers must be required to undertake relevant and appropriate training before being permitted to provide care to people living with progressive neurological conditions like HD. We recommend this as part of the Commission's accreditation and audit processes.

For effective outcomes and the most efficient use of resources, we recommend funding and supporting providers via the NDIS to supply a mix of residential care environments and high-quality services specifically designed for people with HD, in age-appropriate residential facilities, rather

[6] NDIS Operational Guidelines, Principles, Section 4.3
[7] ibid. Objects, Section 4.4.1

than the current approach of relocating people with advanced HD into generalist aged care homes, often in locked dementia wards (see Table 2).

## RESIDENTIAL CARE

Residential care for people with HD should be sufficiently funded and supported to allow these people to remain in a consistent care environment for the remainder of their life, should they so choose. This would include constant access to high level nursing and palliative care as required by HD accredited and educated staff.

**Recommendation**

All people living in residential aged care with HD, regardless of age[8], should be offered the opportunity to move to NDIS SDA/SIL residential accommodation, adequately resourced with specially trained staff available 24 hours a day to provide the high level of care they require to lead dignified lives free from abuse, neglect and exploitation.

[8] Acknowledging that a change to the NDIS Act would be required to extricate from residential aged care those over 65 living with HD.

# COMMUNITY AND RESIDENTAL CARE NEEDS

HD is characterised by uncontrollable movements, cognitive and emotional impairment, behavioural issues, and speech and swallowing difficulties. The behavioural changes are often the most distressing part of the condition and create the greatest challenge for the person with the disease, their family and professional carers.

As the disease and the associated disability progresses, the person requires increasingly sophisticated levels of care. Such care is usually too onerous for the person caring for them at home, considering that this need will continue to increase. Eventually, for most people, residential care will become the predominant outcome. Typically, the age at which someone with HD typically enters residential care is between 30 and 60 years.

Due to frequent breakdowns of family relationships because of the nature of HD, some people live alone and require community-based support services from an early stage. The cognitive disturbances and subsequently altered insight mean that these people may refuse such services, placing themselves in dangerous and unhygienic situations (e.g. spilling boiling water, not showering, or changing their clothes, homelessness, lack of budgeting abilities, behaviours becoming more challenging which can lead to them ending up in the criminal justice system). Thus, a move to residential care may be the only available solution to these difficult circumstances.

In some instances, group homes have been tried with varying degrees of success, depending on the type of support available to residents. Failure of the arrangement has usually been due to the cognitive impairment and behavioural issues associated with HD, combined with inadequate funding and lack of competent staff. However, while a group home or similar community residential arrangement (with appropriate support services) may meet the needs of some, eventually these residents will still need to move to residential care of the type currently supplied by aged care homes as their HD progresses. However, the experience of people with HD in residential aged care is frequently (although not universally) one of neglect bordering on abuse. For example, a person with advanced HD will not be able to eat independently, requiring someone to patiently feed them, whilst monitoring the person for choking. Aged care staffing is not able to provide this level of care, potentially leaving people with HD at risk of chronic malnourishment. The calorific requirements of those experiencing chorea (uncontrollable twisting and jerking movements) are much higher than those of an average aged care resident although this is not often acknowledged, or catered to, in aged care environments. Typically, the recreational activities of a younger person in aged care are designed for those in an aged care setting and are not age appropriate.

We note that people with HD are often forced to move around to different aged care homes due to the inability of facilities to provide adequate care, and/or are admitted to hospital inappropriately, usually because of perceived behavioural issues. These movements and admissions are both disruptive and upsetting to the person with HD (and their family), as well as expensive and time-consuming for healthcare providers. Behavioural issues can largely be prevented or managed if the care environment is well designed, and with carers well trained in HD and who know the resident well.

Currently for most people with HD, the only option when residential care becomes necessary is to move to an aged care home. A small number of patients can access some specialised facilities in NSW, Victoria, SA, and WA. Table 1 provides the current numbers of younger people living in residential age care. Table 2 provides the number of admitted HD patients and permanent residents in aged care facilities from 2014 to 2018.

The data show that close to 60% of people with HD in residential aged care are under 65 years of age. Furthermore, we believe most people over 65 years of age with HD entered residential aged care when they were under 65.

**Table 1** Numbers of Younger People living in Residential Aged Care

| Age Group | Number of Aged Care Residents |
|---|---|
| Under 65 | 5,905 |
| Under 55 | 1,179 |
| Under 45 | 188 |
| Under 35 | 30 |
| **Total** | **7302** |

Department of Health, 2018

**Table 2** Number of HD patients admitted in the previous 12 months and permanent residents in aged care facilities from 2014 to 2018.

| | Age | 2014 | 2015 | 2016 | 2017 | 2018 | 2019 |
|---|---|---|---|---|---|---|---|
| **Admitted in previous 12 months** | **Under 65** | 59 | 49 | 58 | 41 | 47 | 30 |
| | **Over 65** | 30 | 41 | 43 | 35 | 40 | 44 |
| **Permanent Residents** | **Under 65** | 167 | 179 | 185 | 172 | 162 | 149 |
| | **Over 65** | 165 | 179 | 185 | 192 | 186 | 182 |

Source: Special data request from AIHW 2019

## ALTERNATIVE OPTIONS TO RESIDENTIAL AGED CARE HOUSING

### Specialised HD units

Three states (NSW, VIC and WA) have some places in residential facilities that specialise in the care of people with HD - a total of 62 places, with significantly higher staffing ratios that are typically found in residential aged care: Table 3 shows the available places in each state and the relevant provider.

**Table 3** Available places in specialised residential care for people with HD

| Jurisdiction | Specialist facility | Places | Provider |
|---|---|---|---|
| NSW | Huntington's disease Unit,<br>St Joseph's Hospital, Auburn | 14 | St Vincent's Hospital Network |

| | | | |
|---|---|---|---|
| VIC | Arthur Preston Residential Centre, East Burwood | 30 | Wesley Mission Victoria (no longer exclusively HD) |
| WA | Kailis House, Belmont (early stage) | 6 | Brightwater Care Group |
| WA | Ellison House, Carlisle (late-stage) | 12 | Brightwater Care Group |

In the absence of available places in specialised care facilities, provided are examples of alternative housing options for people with HD:

- People with HD in Queensland (3), Tasmania (9) and South Australia (18) receive 24-hour care in community housing. The AHDA is aware of at least 20 people in NSW known to be receiving 24-hour care in the community including NDIS Supported Independent Living (SIL).
- In WA some people with HD find accommodation and care in other specialised facilities such as the Cerebral Palsy Shared Living Home (metro); MS Treendale Gardens (primarily for people with MS), young disabled care residential facility (country); and MS Hamilton Hill.
- A person with advanced HD has recently moved from a secure dementia unit in an aged care home to a specialist disability accommodation (SDA) home with 4 beds in regional NSW, with care funded by from the NDIS SIL. She is much happier, has put on weight and has a staffing ratio of 1:4 as opposed to 1:19 in the aged care home.

# THE ISSUE OF RESIDENTIAL AGED CARE

Here we provide examples of the issue of residential aged care for people with HD:

- **Royal Commission Inquiries**: We note that there have been several federal and state government inquiries into the issue of younger people living in aged care homes (e.g. Senate Inquiries 2004, 2015, Aged Care Royal Commission 2019-20). Without exception, they have produced nothing of value for this cohort.

- **Inappropriate Age**: The average age of all residents in residential aged care has been increasing. At 30 June 2018, 65% of permanent residents were aged 85 and over, up from 57% in 2011, and 50% in 2000. Stays in residential care are becoming shorter and residents have a more complex array of health conditions. Against this background, it can be quite devastating for a younger person with HD to move into an aged care home for what is usually a stay of many years. HD can indeed affect a person by making them more self-centred and less aware of their surroundings. Taking this into account, family and friends can find themselves visiting their loved one in very challenging circumstances. For those younger people in aged care, the care onus usually falls back on the families and friends if they have any, who visit for their stimulation and in many cases aspects of their care (e.g. feeding).

- **NDIS Funding:** Moving into residential aged care means losing some of one's NDIS package if aged under 65 years of age, and all of it if aged over 65.

- **Social Environment:** For younger residents with HD, aged care facilities lack access to age-appropriate social activities and interaction with the residents' peer group. Ideally, younger residents should have access to an enriched residential environment that preferences quality of life. Research has suggested that an enhanced environment can marginally ease some symptoms of HD[9]. Instead, younger people with HD are mostly housed with and treated the same as elderly patients which is not appropriate.

- **Available Staff**: A lack of ongoing specialist training available for professional caregivers combined with a general lack of adequate staffing means that the nature and quality of care are predisposed to be inadequate. Family carers are almost universal in their condemnation of their relatives' care experiences and outcomes.

- **Assisted Eating:** A frequent example of the lack of appropriate care outcomes is the clinical need for people with Huntington's disease to maintain high calorific intake due to their chorea. Residents are reported to be effectively starving in residential aged care due to being left to feed themselves at mealtime, then sent back to their rooms when time is up despite having eaten little.

- **Variations in the Standard of Care:** People with HD in aged care facilities are distributed over many individual facilities and across all regions of the country so that, without a clear pathway of specialised nursing and care training, the quality of care delivered is quite variable, despite the best intentions of the institutions engaged in delivering care.

- **Home Comfort:** Some people may be able to stay at home longer if respite care and appropriate in-home support services were more readily available.

[9] Cruickshank TM, Reyes AP, Penailillo LE, et al. Effects of multidisciplinary therapy on physical function in Huntington's disease. *Acta Neurol Scand*. 2018; 00:1–8. https://doi.org/10.1111/ane.13002

- **Furniture:** There is often a need for an HD-specific bed and chair to avoid potentially significant injury to the person with HD and carers. In our experience, few aged care facilities are willing to provide this expensive specialised and customised furniture. If the person with HD is living in the community with an NDIS package or is living in NDIS residential care, this can now be drawn on to pay for the required equipment. But age discrimination still kicks in in aged care at 65, and even those under 65 in aged care are unlikley to receive NDIS funding to meet this need as it becomes a "buck-pass" betweeen NDIS and aged care.

# THE IMPACT OF THE NDIS

We outline the required needs of the NDIS for people with HD:

- One objective of the NDIS is to assist younger people currently in residential aged care to find '*community-based settings or other age-appropriate settings where possible*.'[10]2—that is, to move back into the community. However, the reality is that HD is degenerative: preventing a move back into the community. It is when all other avenues of care have been tried and they can no longer live in the community, even with a range of support services, that the person with HD requires residential care. Therefore, whatever changes the NDIS brings, it must take account of the fact that people with HD will ultimately require residential care with a high level of support services in their final years — they will not be '*returning to the community*'.

- As the data show (see Table 2), many people with HD receive residential care in the aged care system; some others receive care through specialised units or community-based housing with appropriate levels of 24-hour care. Given the lack of a uniform approach nationally and the different sources of funding for support services, it is likely that the introduction of the NDIS is having varying impacts on people depending on their specific circumstances. However, the few specialised HD units around the country indicate what is needed to provide best-practice care for HD residents. The key to a successful implementation of the NDIS for people with HD is to provide funding for the best practice level of care.

- Those with HD cared for in community housing require funding from the NDIS at a level sufficient to provide the necessary support services enabling them to stay in that accommodation — particularly those services that compensate for the impact of cognitive impairment and the behavioural issues associated with HD. However, we need to be realistic and recognise those residents will ultimately need to access high level residential care. This should not translate to requiring a move to residential aged care as the NDIS should be able to properly support people with HD for the duration of their lives.

- Due to the cognitive changes associated with HD, it is essential that NDIS-funded Service Assessors, Local Area Coordinators, Planners, Support Coordinators and registered providers are familiar with HD, recognise the reason support is needed and the impact of degenerative cognitive impairment.

[10] *Younger people in residential aged care: NDIS eligibility meeting.* Information sheet published by the National Disability Insurance Scheme (updated 22/11/17). Available for download at https://agedcare.health.gov.au/programs/younger-people-in-aged-care/younger-people-in-residential-aged-care-ndis-eligibly-meeting

# HOW TO ADDRESS THE RESIDENTIAL CARE NEEDS OF PEOPLE WITH HD

Because HD is a hereditary disease with a reasonably predictable progression, its impact on the demand for residential care can be forecast, within reasonable limits. This removes a large measure of uncertainty from the costing of public policies relating to the care of those with HD. Therefore, a coherent and holistic approach to dealing with the care needs of those with HD is for the NDIS to directly fund residential care through providers who can deliver both suitable physical facilities and trained nursing and care staff - that is, to fund providers who will supply residential care specifically designed for people with HD rather than the current approach of lumping them in with aged care residents.

The process to reach these recommendations is outlined as follows:

1. Identifying and costing the best practice model(s) of care for residential care of people with HD.
2. Providing funding for the training of professional carers (nurses, allied health professionals, support workers and carers).
3. Approving and funding residential care providers via NDIS who can deliver suitable physical facilities and trained professional staff. These places will need to be funded, according to need, in both metropolitan and regional areas via Specialist Disability Accommodation to cover the disability-specific building requirements.
4. Funding to participants with a care model for Supported Independent Living (SIL) in Huntington's specific disability residential care at a level significantly better than what is currently received in residential aged care which is grossly inadequate.

These recommendations would mean that people with Huntington's disease would no longer be discriminated against and abused within the aged care system, regardless of their age, as they lose out if under 65 and again in different ways if over 65.

# PERSONAL STORIES AND CASE STUDIES

Here we provide personal stories and case studies of those living with HD to support our recommendations.

## A PERSONAL STORY FROM A FAMILY CARER

*I am currently caring for my 59-year-old husband who has HD. As this is a genetic illness, we have had the misfortune of visiting other family members who have been either in respite or full-time care in aged care facilities. Taking our young children to visit their 46-year-old uncle and their 60-year-old grandfather in a geriatric facility where some people in the same ward were in their final stages had such an adverse effect on our children we had to stop taking them to visit.*

*Now that my husband is having respite on occasion, it is unacceptable that he has to be placed where he has nobody with interests or people that he can relate to. Group activities and music are all geared for people nearly twice their age. It is incredibility depressing for the person in care as well as family or friends visiting.*

*I realise we are in the minority; however, young people who require care or respite should be afforded the same respect and concern and dignity that is given to the aged senior citizens. They have already given and lost so much. We were unable to receive respite care at one aged care facility as my husband wasn't eligible: he was too young. They only took people over the age of 65, even though he has been ACAT-assessed and has only ever been in aged care facilities. Where does that leave us, yet again in a hopeless situation? The powers that be need to understand and realise that there have to be hostels and nursing homes that can accommodate young people - the need is greater than you realise, and it needs to be done as soon as possible.*

DF, Central Coast NSW

## A PERSONAL EXPERIENCE

Contributors M & D from the Central Coast, NSW answer some questions about their experiences with young family members with HD in residential aged care.

### How has placing a young family member in age care affected the young, you and your family? What do you think is inadequate about having young people accommodated in aged care? Please provide some personal experiences.

*Our experience relates to the placement of two brothers in the advanced stages of Huntington's disease, one aged 44 and the other in his mid-fifties at the time of placement. They were placed in nursing home age care in two separate facilities in the Newcastle region. The standard of accommodation, facilities and services (and unfortunately the skill of the staff, primarily because of the lack of knowledge of HD and the management of HD sufferers) had and continues to affect the frequency and length of visitations by close family members, especially in one case the children of the resident, who had feelings of helplessness and despair for the hopeless situation of the residents. All these issues impacted on the attitude of the residents, who regularly expressed fear and anxiety about being left by their loved ones in such a 'horrible' place. Neither home provided suitable or appropriate activities for younger people. Even the sing-along sessions in one home did not cater to 'younger' patients. Consequently, the songs not triggering any memories in them, the younger patients had no wish or interest to participate.*

*Standards in nursing homes vary from excellent to poor, depending on one's financial circumstances and the requirements of the resident (age care or otherwise), and facilities that suit the resident's needs are not always available close to the resident's family and friends. In regional areas, this is even more problematic. In placing a loved one in care, when financial reality, proximity and convenience win over 'resident needs', the resident's attitude suffers, and this in turn, as the resident's health and well-being deteriorate, as a result, has a compounding effect on the attitude of family and friends.*

*Living with aged people, and being treated and managed as an aged person, impacts on a younger person's attitude and self-esteem, and without activities and treatment processes that stimulate the mind, and in turn attitude, confidence is lost and positive feelings and thoughts are replaced by negativity and hopelessness.*

*Every effort should be made to ensure compliance with the United Nations Convention on the Rights of Persons with Disabilities, which states that all people with a disability should have the '…opportunity to choose their residence and where and with whom they live on an equal basis with others, and not be obliged to live in particular living arrangements'.*

*Programs such as the National Disability Insurance Scheme should seek to minimise as much as possible the placement of young people in nursing home age care and concentrate on establishing opportunities for them to continue to live in the community by offering more options for age-specific, and even disease-specific, group 'home-style' accommodation, which would have an enormously beneficial impact on their feelings of independence and self-worth.*

## What do you think can be done to improve the circumstances for residential care for people with HD?

- *Specialised Disability Accommodation for Huntington's specific residential care.*
- *Separate wing or ward in nursing homes for younger patients to enable them to interact with one another.*
- *Additional and more regular age-appropriate activity programs.*
- *Higher standards of training for staff related to younger patients and their conditions; e.g. Huntington's, Motor Neurone Disease, etc.*
- *Additional assistance to carers in their own homes to delay as long as possible the placement of loved ones in care.*
- *Higher standards for accreditation (and strictly enforced) for the accommodation and care requirements of younger people in care.*
- *Increase staff levels to allow staff more intimate, personal time with younger people to promote independence and confidence in their performance of everyday tasks, especially those with communication and comprehension difficulties. At the moment nursing homes cater to the elderly and younger people alike, with little differentiation in the management and appropriateness of care. They should not all be put in the one basket: care in nursing homes should be flexible, and as an extension, the types of services offered by staff should be flexible also to suit the individual needs of all patients.*
- *Consideration should be given to limiting the number of large nursing homes in favour of smaller group community homes for younger people - ideally specific homes that cater for specific disabilities and diseases - creating a home-style environment that allows patients to communicate with people in similar circumstances, and one that promotes a more independent lifestyle, rather than the time-constrained, institutional rigidity of nursing home care.*

## CASE STUDIES

**FEMALE CLIENT A, AGE 46**
Located in regional NSW, married with 2 children, aged 18 and 21

Living in a rural setting, the family relied on home-based services to assist, but found that those services could not meet the significant needs of the family and, Client A in particular, as the illness progressed.

The family decided after several stays of 2-3 weeks in respite care, that permanent residential care was required for Client A. This decision was made in consultation with relevant health professionals. The choice of the aged care home was quite limited if they were to keep Client A relatively close to home allowing easy visiting access for the family.

An issue faced when the possibility of an aged care home placement was raised was a concern with going into a care facility full of 'old people'. This concern was realised when Client A moved to the aged care home.

The initial move to permanent care lasted a few months. Client A was not happy there, and the family felt that the care provided was not to an acceptable standard. Concerns included an apparent lack of understanding of Client A's needs as a younger person and HD specific issues.

Client A returned home with provision of some services at home, but this did not work out as Client A deteriorated, and her husband—the main carer—could no longer manage, even with services to assist.

This resulted in seeking a position in a different aged care home. This has been more successful, but not without trouble.

Challenges faced in each aged care home have included providing activities of interest to Client A as many of her interests and abilities differ markedly from those of other residents. As well, staff have not treated Client A in line with her age and illness, given her situation is quite different from most residents.

**MALE CLIENT B, AGE 56**
Located in metropolitan WA, widowed with 2 sons

Client B was widowed in 2010. He remained at home with his 19-year-old son with support from Home and Community Care. An older son took over his care two years later. From 2013, it became more difficult to support Client B at home and a suitable placement was sought. It was 12 months before a placement, in an aged care facility, became available. The adjustment for Client B from home to living in an aged care facility was very difficult. He had little in common with other residents who were much older than him. Additionally, the care environment was not conducive to either his grandchildren or other immediate family members visiting. Client B became isolated, withdrawn and very unhappy.

The situation changed for Client B when he was able to be placed at a residential care facility for younger people with a disability. In this facility, Client B has his own room and a small living area with a kitchenette. Since being there his family has re-commenced visiting regularly. Client B feels very comfortable having his grandchildren come to his room. It gives privacy and they can visit without needing to engage with other residents in the facility. Client B reports he is much happier now that he is not living in aged care. This placement is only possible as Client B was successful in obtaining CAP funding from the Disability Services Commission (WA).

**MALE CLIENT C, AGE 40**
Located in regional NSW, married with a child aged 9

Client C was living at home but fairly rapid deterioration physically, cognitively and behaviourally necessitated placement in an aged care home when he was aged 38.

There was an initial perception issue for Client C with the concept of going into an aged care home full of 'old people'. Once the need for care was identified, there was a real issue finding an aged care home in reasonable proximity to home that would accept younger people. Client C was initially placed in an aged care home 100km away from home, as no place could be found locally. A placement closer to home became available about two months later.

Client C reacted very badly to some nursing staff, possibly due to their lack of understanding of HD symptoms, and his reaction to some staff of non-Australian background was very aggressive.

This challenging behaviour resulted in the aged care home seeking expert assistance which led Client C being placed in the local hospital, then moving to a short-term acute care facility for several months. At this time, further training was provided to the aged care home, and the Dementia / Behaviour Assessment and Management Service was engaged to assist. Client C subsequently returned to the aged care home, and the situation is significantly improved.

Client C's wife and child have found it very difficult visiting him in the aged care home setting where he is so much younger than other residents.

**FEMALE CLIENT D, AGE 43**
Located in metropolitan WA, single

Client D is single and before her admission to a low-level aged care facility was living independently. She was supported in her independent living by her older, unwell mother. Before her first admission to an aged care facility, she had several hospital admissions for acute mental health issues which were followed by extended periods of emergency respite. Client D was admitted to low level aged care in 2008 at age 41. Client D did not settle in aged care and was discontented and unhappy. She remained in aged care until 2014 when her mother was eventually able to secure a place in a group home for younger people. This option became possible as a result of a funding package through the state Disability Services Commission (WA).

**A TASMANIAN EXAMPLE**
Re-located from Tasmania to Victoria

A younger person with HD in Tasmania (now 40 years of age) spent two years in aged secure Mental Health Service care—their long-term accommodation unresolved. The permanent solution found has been to move them to accommodation in Victoria.