

Huntington's New South Wales



Making A Decision About Residential Care

Supported by NSW Health

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Making the decision to move into a residential care facility can be one of the most difficult decisions faced by people with Huntington Disease (HD) and their carers.

For people with HD, it can seem like giving away the independence that they have fought for so long to maintain.

For carers and family, it can be a decision marked by feelings of sadness and guilt.

This fact sheet explores the process involved in making the decision about residential care and presents some of the issues that need to be taken into consideration when choosing a residential facility.

Deciding on Residential Care.

There are many factors that contribute to the decision for a person to move into residential care.

Every situation is different. Some people with HD can remain in the community indefinitely if they have a carer.

In practice some of the factors that might be associated with the decision include:

- The physical and or emotional demands of providing care at home have become too much. For example walking deteriorates, incontinence becomes an issue.
- The available support services are no longer able to meet the needs of the client and carer.
- The behavioural changes associated with the disease have become too difficult to manage.
- The person requires nursing care.
- The risks associated with the person remaining at home are too high.
- The person may need 24 hour supervision and care but it is not financially possible for the carer to give up work.

In some instances, the person with HD may make the decision to move into residential care themselves. In other instances, they may be very reluctant to move out of the family home.

The Transition in to Residential Care Can Be A Positive Experience:

Many people with HD who move into residential care find that, rather than restricting their independence, they are able to engage in the activities that they enjoy and be freed up from the activities like shopping, cleaning and meal preparation that they have been finding increasingly difficult and tiring.

The move into residential care also enables the carer and family to spend quality time with the person with HD, engaging in 'normal' activities, rather than spending the majority of time providing 'hands on care'.

Sometimes There May Be Difficult Hurdles That Need To Be Crossed In The Process:

Despite the need for residential placement, the people involved with the decision can find the process very distressing.

Carers frequently experience difficult emotions such as sadness and guilt and loss. This is an understandable reaction. It may be important to talk about this experience with someone you trust that understands the situation. This may be a friend, family member, your GP or your key worker from the NSW Huntington Disease Service.

For the person with HD, facing the transition into residential placement can be extremely confronting. The person may respond in a number of ways. They may become angry or

sad. It may be that the person does not have clear insight into their deficits and the impact that they are having on the carer. They may feel that it is unreasonable to consider moving out of home if this is the case.

In instances where there is conflict about the decision to consider residential placement, it might be useful to talk through the issues with a social worker from the NSW Huntington Disease Service who will be able to make recommendations and support those people involved. In cases where there are significant risks to either party, the NSW Guardianship Tribunal may be contacted to consider the appointment of a guardian who would have legal authority to make decisions for the person with HD.

Accommodation Options

The type of facility required is determined by the amount of care that an individual requires. There are 2 main accommodation options:

Hostels (Low level care residential facilities)

Hostels are funded by the Commonwealth Government and 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)

Nursing homes are also funded by the Commonwealth Government and provide 24 hour nursing care for residents. Nursing homes are staffed by registered and enrolled nurses, nursing assistants or personal care attendants.

What Will It Cost?

There are 2 types of payments that residents are asked to make:

1. Daily care fees

Each resident pays a basic daily fee. For pensioners it is approximately 85% of the pension, for part-pensioners and non-pensioners, the daily fees are based on income.

2. Accommodation payments

Hostel residents may be asked to pay an *accommodation bond* (depending on assets).

Nursing home residents may be asked to pay an *accommodation charge* (depending on assets).

NB Service providers are required by law to care for people who cannot afford to pay a bond or charge. A number of places are reserved for these people based on local need. Information about fees is available from your local Centrelink Office.

The Process

Again, the decision to consider residential care can be extremely difficult. It might be useful to discuss the idea with a social worker from the NSW Huntington Disease Service who can talk through the issues and assist you through the process. Assessments as to whether hostel or nursing home care is needed are made by your local Aged Care Assessment Team (ACAT). You can directly approach your local ACAT or ask your social worker to do this for you.

You may also wish to speak with your GP and/or HD specialist about the issues.

The ACAT

The Aged Care Assessment Team will need to undertake an assessment to determine the level of care required by an

individual prior to placement. This is necessary if the person's needs are best met in a hostel or nursing home.

Choosing a Facility and Waiting Lists

Once the ACAT assessment is completed, the assessment paperwork is required to enable the person's name to be put on waiting lists for appropriate facilities (either Hostel or Nursing Home as dictated by the assessment).

Most hostels and nursing homes have waiting lists due to the high demand for placement. Because of this high demand, it is important that you choose a number of facilities that you consider would meet the needs of your family member and put their name on at least 5 waiting lists.

Again, a social worker from the NSW Huntington Disease Service can assist with helping you to select appropriate facilities. Whilst the social worker can make suggestions, it is important to visit residential facilities in order to decide whether they might be appropriate for the person with HD. One of the most significant challenges families face is the tendency to imagine their own quality of life in a given facility rather than objectively considering whether the facility can meet the very specific needs of their loved one with HD.

On the following page, there is a list of suggestions of what to look for when visiting residential facilities - this guide will help you to make this decision.

Specialist HD Facility – Huntington Lodge, Lottie Stewart Hospital

Huntington Lodge is a specialist, state-wide HD facility managed by Wesley Mission, Sydney and located at Lottie Stewart Hospital, Dundas, Sydney.

Places in this residential program are limited and access is

based on age and assessed care needs criteria, coinciding with a vacancy.

Checklist of Things to Consider When Choosing a Facility

What are your first impressions?

Is the facility welcoming and friendly?
Is there a homelike environment?
Does it smell good?
Do other residents appear well cared for?
Is the temperature comfortable?
Is the lighting and ventilation good?

What are the services and care like?

Is there a good activity program?
Are religious or spiritual needs met?
What are the residents' individual rights? - own belongings, mail, pets, religious beliefs.
Can residents have their own doctor?
Are other services such as physiotherapy, hairdressing etc provided?
Can increased care needs be catered for?
Does the facility have suitable equipment (ie chairs, beds) to facilitate the care of a person with HD?
Is the facility able to cater to the dietary needs of a person with HD (ie provision of calorie-rich meals, the flexibility to provide smaller meals more frequently throughout the day)?

Are the buildings and surroundings suitable?

Is the security satisfactory? - Is there freedom to move around?
Is there adequate access to bathroom facilities from the rooms?
Are there secure and interesting outdoor areas?

What are the staff like?

Do staff appear to treat residents and their visitors with respect?

What training have staff had?

Has the facility looked after a resident with HD before?

Are staff interested in learning more about HD (ie having an education session about HD)?

What is the staff to resident ratio?

How many staff are on duty at different times?

Are your questions received positively?

Does staff morale appear to be good?

Are family members and visitors catered for?

Are visiting times and access for family and friends satisfactory?

Can outings with family members be easily arranged?

Can the family come and help the person with self care (ie eating) if desired?

Are there areas for families to get together?

Is there a residents' or relatives' committee?

Is there adequate access to and from the facility for residents and visitors?

Information about the facility

What is the fee structure - has it been adequately explained?

Did you receive good written information?

Fact Sheets

- Huntington's Disease in the Family – A Booklet for Young Children
- Huntington's Disease – A Fact Sheet for Teenagers
- Talking to Children about Huntington's Disease
- Presymptomatic Testing – The Consumer Experience
- Understanding Challenging Behaviour in Huntington's Disease
- Living with Someone who has Huntington Disease
- Making a Decision About Residential Care
- Guidelines for Meeting the Nutritional Needs of People with Huntington's Disease
- Eating and Swallowing Difficulties in Huntington Disease
- The Importance of Dental Care in Huntington Disease
- Communication and Huntington Disease

*These Fact Sheets are available from the
Huntington's New South Wales
Please see the back page for contact details.*

Helpful Contacts

Huntington's New South Wales

PO Box 178, West Ryde, NSW 1685
Tel: (02) 9874 9777
STD Free Call: 1800 244735
Fax: (02) 9874 9177
Website: www.huntingtonsnsw.org.au
Email: hdassoc@huntingtonsnsw.org.au

NSW Huntington Disease Service

Jet Aserios & Cecilia Lincoln (02) 9845 6699
Social Workers, Westmead Hospital

Outreach Service (02) 9845 9960
Westmead Hospital

For further information on Huntington Disease, a membership form, or details of HD services in NSW, please contact Huntington's NSW

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