

## Huntington's disease explained

Huntington's disease (HD) is a neurological condition caused by the inheritance of a defective gene. The death of brain cells in certain areas of the brain results in a gradual loss of cognitive, physical and emotional function. HD is a complex and severely debilitating disease, for which there is no cure.

The most common symptom is jerky movements of the arms and legs, known as 'chorea'. Chorea usually starts as mild twitching and gradually increases over the years. A person with HD may also have difficulties with speech, swallowing and concentration.

### HD symptoms

There are three groups of symptoms for HD.

#### Physical symptoms

- Mild twitching of the fingers and toes
- Lack of coordination and a tendency to knock things over
- Walking difficulties
- Dance-like or jerky movements of the arms or legs (chorea)
- Speech and swallowing difficulties.

#### Cognitive symptoms

- Short-term memory loss
- Difficulties in concentrating and making plans.

#### Emotional symptoms

- Around one-third of people with HD experience depression
- Mood swings, apathy and aggression.

### A slow, progressive disease

HD is caused by a defective gene. This gene is passed on from parent to child, but the condition isn't obvious at birth. The symptoms usually, but not always, first appear when the person is approaching middle age. HD is a slow, progressive condition that affects people differently. A person with HD may live for 15–25 years after developing the first symptoms. Diagnosis is based on a family history of HD (when known), genetic testing, plus assessment of physical, neurological and emotional symptoms. There is no cure for HD.

### Gene testing is available

A child born to a person who carries the HD gene has a 50 per cent chance of inheriting the gene and developing the disease. People at risk can take a test to see whether they have inherited this gene. A person must be at least 18 years old and want to know their gene status before they can have the test. Deciding whether to take the test is a personal choice. Counselling is available to help the person with HD and their family, carers and friends to cope with the genetic result.

### Type of help available

Individual and family support workers are employed in all regions to support people with HD, those at risk and their families. Services include:

- Information and counselling
- Assessment and referral
- Practical help with in-home support
- Practical help with accommodation and respite
- Ongoing support for carers
- Holiday and volunteer programs.

## Where to get help

- Your GP or specialist
- Your nearest Department of Human Services office.
- The Australian Huntington's Disease Association Tel. (03) 9563 3922

## Things to remember

- Huntington's disease (HD) is a neurological condition caused by the inheritance of a defective gene.
- Symptoms often don't appear until the person is in their thirties or forties.
- Not all people with HD experience the same symptoms.

**This page has been produced in consultation with, and approved by:**

Huntington's Victoria

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