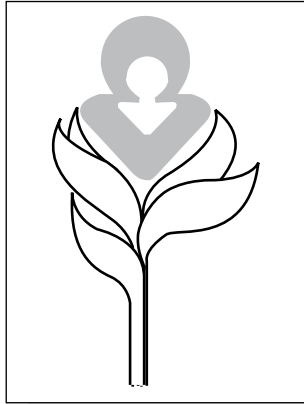


Huntington's Disease Association



Information for Teenagers

Fact Sheet

Information for Teenagers

Huntington's disease is an hereditary illness which affects the brain. It occurs when a person inherits a faulty copy of a particular gene. Every person has 2 copies of every gene, one of which they receive from their mother, and one from their father. A person with Huntington's disease has one copy of the gene which is the normal size, and one copy which is enlarged. The faulty gene causes certain brain cells to die.

If a person has a parent with Huntington's disease they are born with a 50% risk of inheriting the disease. This means they have as much chance of not inheriting the gene as inheriting it. Every child of a parent with Huntington's disease has the same chance.

Many people wonder about whether they have inherited Huntington's disease – there is a genetic test which will answer this question. Some people feel that they need to know so that they can plan for the future but most people feel that they can live more comfortably if they do not know for sure. You normally need to be 18 to have a predictive test. The genetics clinic will be happy to discuss this with you.

You can go and discuss this with the clinic without committing yourself to being tested, the service is confidential. If you are under 18 but would like to talk to the staff at the clinic they would be happy to see you. The genetics clinic can also be used as a source of information.

A referral to the genetics clinic can be made through your GP.

The illness most commonly develops between the ages of 30 and 50 and begins with mild symptoms in the early stages that progress slowly. Many people can still work for many years after the onset of symptoms.

The faulty gene affects the way that the brain functions and as the disease progresses the affected person can change emotionally (they may become short tempered and angry), physically (they may have jerky movements and their speech may be difficult to understand) and cognitively (they may find it hard to concentrate and remember things).

When someone in the family has Huntington's disease or is at risk to the illness it can be a very difficult time. You may feel very isolated or angry or resentful and worried about your family. You may feel frightened. It is important that you find someone to talk to about these issues, perhaps a friend or relative to whom you feel close.

If you would rather talk to someone who is unrelated to you the Huntington's Disease Association has a team of Regional Care Advisers who would be able to help you. They can be contacted through our Head Office on 0151 298 3298. The genetic clinics also would be happy to see you to discuss any areas of concern.

There are other young people who may be experiencing similar difficulties. It may be helpful for you to meet up with them. This could be arranged through the local Branches of the Association.

You may also like to use our Message Board facility on the internet to share your concerns.

Please visit <http://www.hda.org.uk/board/index.php> for more information.

Fact sheets available from the HDA:

- General Information about Huntington's Disease and the HDA
- Predictive Testing for Huntington's Disease
- Talking to Children about Huntington's Disease
- Information for Teenagers
- Eating and Swallowing Difficulties
- Huntington's Disease and Diet
- The Importance of Dental Care
- Communication Skills
- Behavioural Problems
- Sexual Problems
- Huntington's Disease and the Law
- Huntington's Disease and Driving
- Advice on Life Assurance, Pensions, Mortgages etc
- Seating, Equipment and Adaptations
- Checklist for Choosing a Care Home
- Advance Decision to Refuse Treatment (ADRT)
- A Carer's Guide
- Challenging Behaviour in Juvenile Huntington's Disease
- A Brief Guide to Juvenile Huntington's Disease for Children's Hospices and Palliative Care Service
- A Young Person with Juvenile Huntington's Disease at School

All Fact sheets can be downloaded for free from our website:
www.hda.org.uk or ordered direct from Head Office

For a publication price list/order form, membership form, details of our Regional Care Advisers and local Branches and Groups, please telephone, email or write to:

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