



Talking to Children about Huntington's Disease

When considering how to talk to children about Huntington's disease there are two main issues. The first relates to talking to them about an affected parent, relative or friend, in order to explain the affects of the illness. The second concerns the genetic and hereditary nature of the illness and the implications for the child.

Both of these issues are very difficult and distressing to face. It may be hard to find the right time and the right age to discuss them. It may be tempting to totally avoid discussing them at all.

In some ways it may be easier for a young child to cope with the implications because when you are nine or ten something that may or may not happen until you are forty is a very remote concept!

Not telling children does not take the reality of the situation away. In fact it makes children powerless to make informed choices about their lives as they grow up.

Children are far more perceptive than we think. They will be aware that a family member is ill or has changed.

Often the person with Huntington's disease may be less tolerant or more short tempered and

children may feel that it is in some way their fault. Even if this is not the case children are aware of anxieties and tensions within the home and if they are not given factual information they use their imagination to fill in the gaps in their knowledge. They may perceive themselves as rejected and unloved. However if their questions are answered in a supportive and loving, open and honest environment a lot of their fears and anxieties will be addressed. If they feel they will be listened to and understood they will ask more questions as they arise.

Relationships between parents and children can suffer too if a parent is trying to hide the facts. Even very young children are astute at realising when you are not telling the truth.

It is almost certain that children will find out the facts one day. Genetics are taught as part of the national curriculum, and genetic illness is currently highlighted in the media nearly every day.

Research has shown that many people who were not told until they were adults feel very angry and resentful that the information had been kept from them especially if they have already made major decisions in their lives.

Parents often fear that telling their children will have a detrimental affect upon their lives. However

being aware of the situation allows them to cope more effectively and having the knowledge will help with future decision making.

Talking to children about Huntington's disease

As a parent you know your child best, and will know how they deal with new and potentially distressing information. The following guidelines may help you to decide how best to approach the subject with your child.

It is much better to introduce the topic into a conversation in response to questions by the child. Give only a basic amount of information and gradually build up the information about the illness in response to demands from the child.

You need to feel comfortable about doing this, and to be prepared for lots of questions when you least expect them! If you do not know the answers to their questions, be honest and say so but be prepared to find out.

It may help you to think about the type of questions that your child may ask and to have prepared some answers. In this way even if the moment catches you off guard you have some idea of what to say!

Here are some ideas:

What is Huntington's disease?

It is an illness that affects our brain.

Why do people walk, talk and eat in a funny way when they have Huntington's disease?

Our brain works a bit like a computer sending messages to different parts of our body. It controls the way we think, eat, walk and talk so if it is not working properly the messages are not clear and our body cannot work properly.

Sometimes I think Daddy doesn't love me anymore because he always seems grumpy and cross.

The illness can make it difficult for Daddy to show that he still loves you, but he does. If you feel sad or upset anytime then talk to me about it.

Can I catch Huntington's disease?

No – but there is a chance that you may get it when you grow up but you may live to grow old without getting it.

Can the doctor make it better?

Although doctors can't make people with Huntington's disease completely better they can give medicines to make it easier for them to think, walk, talk and eat. Doctors all over the world are looking at ways to make people with Huntington's disease completely better. One day they will be able to, but not yet.

Who can help?

The Association has a team of Regional Care Advisers who will be happy to support you and your children through this time. The staff at the genetics clinic would also be happy to offer support and advice to you and your child. The Association has a booklet for younger children and also a fact sheet for teenagers. Please contact Head Office on 0151 298 3298 for details.

Fact sheets available from the HDA:

1. All about the Huntington's Disease Association
2. General Information about Huntington's Disease
3. Predictive Testing for Huntington's Disease
4. Talking to Children about Huntington's Disease
5. Information for Teenagers
6. Eating and Swallowing Difficulties
7. Huntington's Disease and Diet
8. The Importance of Dental Care
9. Communication Skills
10. Behavioural Problems
11. Sexual Problems
12. Huntington's Disease and the Law
13. Huntington's Disease and Driving
14. Advice on Life Assurance, Pensions, Mortgages etc.
15. Seating, Equipment and Adaptations
16. Checklist for Choosing a Care Home
17. Advance Directive or "Living Will"

Booklets

Huntington's Disease in the Family (1997)

A booklet produced for young children

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

Huntington's Disease Association

Neurosupport Centre, Norton Street, Liverpool L3 8LR

Tel: +44 (0)151 298 3298 Fax: +44 (0)151 298 9440

Email: info@hda.org.uk Web: www.hda.org.uk