Huntington’s Disease

A teacher's guide
Introduction
The purpose of this fact sheet is to provide you with information about Huntington’s disease and the ways that Huntington's impacts on young people in school. Also, how they are affected by having Huntington’s in the family, and how it may affect their home life.

What is Huntington’s disease?
Huntington’s disease (HD) is a hereditary neurological disorder. Put simply, it is a hereditary illness that affects the brain and the body. Each young person whose parent carries the Huntington's gene has a 50% chance of inheriting the gene. At the moment while there is no cure for it, scientists around the world are searching for a treatment that will either silence the gene, so stop it from developing, or reverse the genes progress.

What does the Huntington's gene do?
Physical symptoms
Huntington’s normally develops in adults between the ages of 30 and 45, although symptoms can begin to develop at an earlier age. The gene affects the brain, notably in the basal ganglia. This in turn leads to dance like movement in the body.

This can manifest as:

- Shaky hands or slight twitchy movements
- Loss of balance co-ordination
• Speech
• Swallowing
• Weight loss

For a more detailed explanation of the Huntington’s disease and the symptoms involved, please visit our website www.hda.org.uk

**Neurological Symptoms**

• Depression
• Loss of sleep or a change in the sleep pattern due to a loss of apathy
• Memory can also be affected with either long or short-term memory loss
• People can also become very compulsive

When both the physical and neurological elements of Huntington’s combine it becomes a truly devastating illness, and like so many other things in life, what is true for one person may be completely different for another, even in the same family.

Ultimately the person with Huntington’s will die, although this will not be from the Huntington’s itself, people normally die from an associated illness, such as pneumonia or an infection. A bad fall or choking can also lead to a loss of life.
Being a young carer

For many young people with Huntington’s in the family, they have to take on additional responsibilities at home. Many find themselves suddenly becoming a young carer for a member of the family.

Some young people who are also young carers struggle in school because they have to physically be there for a parent or sibling, this can result in them playing up; especially when they are told that they have to stay behind for one reason or another. It is also important to mention that many do not talk about being a young carer, or ask for help or support, because they don’t want people to think that they can’t manage.

Isolation

The latest figures for those with Huntington’s suggest there are 1 in every 10000 people. This means that it actually affects a small percentage of the national population, and in turn, this means that young people living in Huntington’s families feel very isolated. This is magnified when they don’t feel they can bring friends home; when they don’t know how mum or dad will be on the day.

Embarrassed

Imagine that Mum has Huntington’s, and due to this, her body movements can give the impression that she may be drunk when she comes to pick up her 15 year
old daughter from school. The final thought many of the pupils will have is that she is drunk, other thoughts will probably include; she’s wired, mental, or not right in the head. These will, in all probability, also be associated with the daughter. Again, we can begin to understand why the daughter may feel embarrassed about her mum coming to school to drop her off, pick her up, or attend parent’s evenings.

In lessons

Huntington’s disease is now on the national curriculum and it is covered in hereditary/genetic illnesses in science. Picture the scene; 30 young people in the class, one of them lives in a Huntington’s family. The teacher explains what the class is going to be discussing i.e. Huntington’s, then asks if anyone in the class is living with, or knows anyone, who has Huntington’s. Given the rarity of the illness, the one young person in the class who is living in a Huntington’s family, will not put their hand up.

Finances

Many families, as the disease progresses, will potentially come into financial difficulties. This is because the parent with Huntington’s will get to a stage when they are unable to continue working. Then the other parent may have to give up their role/work in order to become a full-time carer for their partner. This means that a family with a joint income can become a family with a single or no income relatively quickly. The knock-on effect of this is that they may not be
able to afford as many luxuries or necessities as before. So, school uniforms etc can take a backseat in the family’s finances.

**Perseveration**

A common symptom of Huntington’s can be paranoia or fixation on a particular area or thing, for some parents this can be their children’s wellbeing. This can show in several different ways; a slight cold could mean that they have to stay off school and get better. A cut finger could result in a trip to the hospital.

For many young people with Huntington’s in the family, they have to grow up quickly; they have to become the carer to a parent and sometimes parent to a sibling. While many of them do an excellent job, it is still an extreme amount of responsibility for a young person to take on, especially when they also have their education to think about and the pressures that can also place on them.

**Grieving**

For many young people they will potentially go through the grieving process twice for their parent with Huntington’s. This is because many people with Huntington’s will ultimately require residential nursing care: and for the young person, this can be a traumatic experience, especially if they been the one providing the majority of care for their parent.
Residential care

As stated above, the parent with Huntington’s may eventually reside in a care home. This has implications for the young person as they will want to continue to see their parent. Problems can arise when they are unable to go to the care home at the desired time.

Mirror effect

A young person growing up and caring for someone in a Huntington’s family will see everything from diagnosis and testing, to symptoms, deterioration and ultimately death. For many this is the same as holding up a really large mirror and allowing them to see a potential future for themselves in 20-30 years’ time. Each young person is at 50% risk of inheriting the Huntington’s gene. When and how this information is shared with them depends on their family. There is no right or wrong way and we are not here to condemn or condone the parent’s decision.

Support

We are here to support the young person because as there is no right or wrong way to tell them, there is no way of knowing how they will react to the news either. They could bury their head in the sand, feign interest, really get involved, find out more, act up or lash out. It is as different as they are. The important part is to support them and give them the chance to talk, ask for support or even talk about everything but Huntington’s until they are ready.
Huntington’s disease is in my family, this means:

- I am / may be a young carer
- I might not have time to do my homework/course work
- I may be late in the morning
- I may have to go home at lunch time
- I can’t stay after school
- My uniform may not be washed/ironed/new
- I may not be able to go on school trips
- There are times when I may have been up all night
- My parent may not live at home
- I want to learn
- Huntington’s does not define me, I am still a young person
Fact sheets available from the Huntington’s Disease Association:

- General information about Huntington’s disease and the Huntington’s Disease Association
- Predictive testing for Huntington’s disease
- Talking to children about Huntington’s disease
- Information for teenagers
- A young adult’s guide
- 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 services
- A teacher’s guide
- A young person with Juvenile Huntington’s disease at school

All fact sheets can be downloaded free of charge from our website www.hda.org.uk or ordered by phone 0151 331 5444 or email info@hda.org.uk

For a publication price list/order form, membership form, details of our Specialist Huntington’s disease Advisers and local Branches and Support Groups, please phone 0151 331 5444 or email info@hda.org.uk