TEACHER'S NOTES
WHAT IS HD?

OVERVIEW

Aimed at key stage 4 pupils. This is a simple comprehension activity for pupils to consider the main features of Huntington's disease (HD).

LEARNING OBJECTIVES

- To understand the features and symptoms of HD.

CURRICULUM LINKS

- **KS4:** Human health is affected by a range of environmental and inherited factors, by the use and misuse of drugs and by medical treatments
- **KS4:** chemical and electrical signals enable body systems to respond to internal and external changes, in order to maintain the body in an optimal state

Activity

- Introduce the genetic condition Huntington's disease
- Show the film Luke's story on **www.genesareus.org**
- Give pupils the worksheet to complete
- After pupils have answered all the questions, ask the class to consider the following statement: 'If I were at risk of HD I would want to find whether I would develop the condition in the future'
- Ask pupils to discuss this with the person next to them
- Draw a line on the board with 'agree' written at one end and 'disagree' at the other end of the line. Ask pupils to write their initials somewhere on this line to reflect how they feel about this choice.
- Invite pupils to explain their choices to the class. You might like to tell pupils that the majority of people at 50% risk of HD choose not to find out.

ANSWERS

1. Doctors describe Huntington's disease as a progressive neurodegenerative disease – why is that?

HD is called neurodegenerative because it results in the loss of neurons in the brain. It is progressive because neurons continue to be lost throughout the course of the disease.

2. What other neurodegenerative conditions can you think of? Do they share any similarities with HD?

Pupils might suggest Alzheimer's disease (AD) or Parkinson's disease (PD). These both share similarities with HD, in particular gradual dementia and often personality changes. AD does not typically cause movement disorders. Some pupils may have heard of other neurodegenerative conditions, such as amyotrophic lateral sclerosis (ALS or also known as Lou Gehrig's disease) or spinal muscular atrophy.

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ANSWERS continued

3. Copy the chart below and tick those symptoms that you think are caused by HD and put a cross by those you think are not

Behavioural disturbances	✓	Irritability	✓
Unable to have fun	✗	Persistent cough	✗
Feeling restless	✓	Irritated skin	✗
Desire to see friends more	✗	Difficulty swallowing	✓
Jerky movements	✓	More talkative	✗
Unsteady gait	✓	Problems with speech	✓
Loss of memory	✓	Uncontrolled movements	✓
Sleep disturbances	✓	Not caring about things	✓
Hair falling out	✗	Walking more quickly	✗
Depression	✓	Personality changes	✓

4. Doctors are able to predict whether an individual will develop HD in adulthood. If you had an affected parent or grandparent, would you want to find out if you were going to develop HD or not? What factors might influence your decision?

There are no right or wrong answers to this question; it is to start pupils thinking about the decision-making process for people at risk of HD. Lots of factors will influence an individual's decision, such as the attitudes of their family or their outlook about wanting to know more about the future. Some people are better are living with uncertainty than others.

FURTHER information

- The NHS website has a good introduction to HD, which includes a short film with a patient affected by early stages of HD **www.nhs.uk/conditions/Huntingtons-disease**
- The Huntington's Disease Association (HDA) provides excellent information about the condition **http://hda.org.uk**
- American website called 'Your Genes, Your Health' has animations and films to help explain HD to school pupils. It is pitched above GCSE-standard but would be accessible to able pupils **www.ygyh.org**

EXTENSION

- Pupils could investigate the treatments that are available or in development by doing research online. You might want them to focus on one particular area, such as using stem cells in the future to treat HD.

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STUDENT WORKSHEET

WHAT IS HD?

Huntington's disease (HD) is a rare genetic condition that affects the brain. On average, people are 35 years old when they begin to show symptoms of HD and they usually die 15-20 years later. In very rare cases, HD affects younger people, but this is very unusual. People with HD are ill because they lose certain brain cells (neurons), which affects them in various ways.The neurons die throughout an individual's life, but because the brain has so many, it takes a while before the loss of neurons begins to noticeably affect their health.

1 ***Doctors describe Huntington's disease as a 'progressive neurodegenerative disease' – why is that?***

2 ***What other neurodegenerative conditions can you think of? Do they share any similarities with HD?***

Your brain is made of billions of inter-connected neurons, forming a very complex network. When neurons die, the brain is no longer able to work properly. Depending on which particular neurons die leads to different symptoms. In Huntington's disease the symptoms include physical, mental and emotional changes.

3 ***Copy the chart below and tick those symptoms that you think are caused by HD and put a cross by those you think are not***

Behavioural disturbances		Irritability	
Unable to have fun		Persistent cough	
Feeling restless		Irritated skin	
Desire to see friends more		Difficulty swallowing	
Jerky movements		More talkative	
Unsteady gait		Problems with speech	
Loss of memory		Uncontrolled movements	
Sleep disturbances		Not caring about things	
Hair falling out		Walking more quickly	
Depression		Personality changes	

HD cannot be cured, but there are a number of treatments that can help to reduce the severity of the symptoms. Traditional drugs are used to treat the individual symptoms of HD. For example, drugs used to treat depression in people not affected by HD are also used to treat depression in people with HD. There are also treatments to help control involuntary movements and speech therapy is used to help with speech and swallowing problems.

If someone has had a genetic test to find out whether they will develop HD in the future, it will not predict which symptoms someone will experience or at what age. A predictive genetic test is done before someone experiences symptoms, but if they have a test once they are experiencing symptoms it is a diagnostic test.

Friends and family having to witness the progression of HD in an individual can find the personality changes such as increased irritability and depression particularly difficult. It is very hard to know that the condition will continue to get worse.

4 ***Doctors are able to predict whether an individual will develop HD in adulthood. If you had an affected parent or grandparent, would you want to find out if you were going to develop HD or not? What factors might influence your decision?***