

Huntington's disease

Introduction

This activity gives a short review of the inheritance of disease caused by a dominant allele. It asks students to justify their opinions on the use of genetic tests for a late onset disease.

The activity

This activity could be used as the basis for discussion in class or for written work depending on the time available and the skills to be practiced. It should take about half an hour.

Suggested answers to questions

1. Which individuals in the family tree may have inherited Huntington's?

Joanne, Ben, Sam, Zoë, unborn baby

2. Joanne is about to become a grandmother for the first time. Should she find out if she has the disease?

If Joanne considers only her own needs she may decide that she does not want to know as there is no cure. She may decide that the consequences in terms of issues such as employment or life insurance also mean that the costs are greater than the benefits.

However she also has a duty to her children and to her unborn grandchild. Their interests may be different. If she has the test it helps their decisions.

3. If she decides to have the test should she tell her son the result? *However painful, most people would believe that she has a duty to her son to inform him. The result has a direct bearing on his own life and that of his unborn child. He still has the autonomy to decide not to act on the information.*
4. Should Sam and Marian ask for genetic testing for their unborn baby?
If Sam's test is negative the issue does not arise.

The final decision could be influenced by whether Sam and Marion would regard abortion as ethically acceptable if the baby were found to carry the Huntington's gene. Some people take a principled position that the unborn child has a right to life and that the parents are ethically wrong to choose abortion. Others take a utilitarian approach and consider that although abortion is always bad there are some outcomes

How Science Works

Hi Decisions and opinions on ethical issues are based on values. An individual's view on an issue may be based upon a religious or moral position.

Hj Some decisions involve balancing the rights of certain individuals and groups against those of others.

Hk A utilitarian approach is to argue that the right decision or choice is the one that leads to the greatest good for the largest number. It can also be argued, however, that some actions are wrong, even if they lead to good outcomes.

Science explanations

Cb In sexual reproduction, a single specialised cell from a female merges with another specialised cell from a male. Each of these sex cells contains a randomly selected half of the parent's genes. The single cell which they form then contains a full set of genetic information, one of each gene pair coming from a different parent. This process means that there is a very large number of possible combinations of the parents' genes, so offspring can be quite varied in characteristics.

Cd Each cell contains two genes with the same function, and each gene may occur in two or more different versions called alleles. The way one allele affects cell function may dominate the effects of other alleles. This allele is known as dominant, and the others as recessive alleles.

which are even worse. Whether an awful disease which affects people only in late adulthood is such an outcome is a difficult decision. If they would want an abortion if the baby has the Huntington's gene then many people would consider that Joanne may have a duty to have the test and to inform her son of the results.

There are no right answers but students should be encouraged to consider all possible consequences and to justify whatever choices they make.

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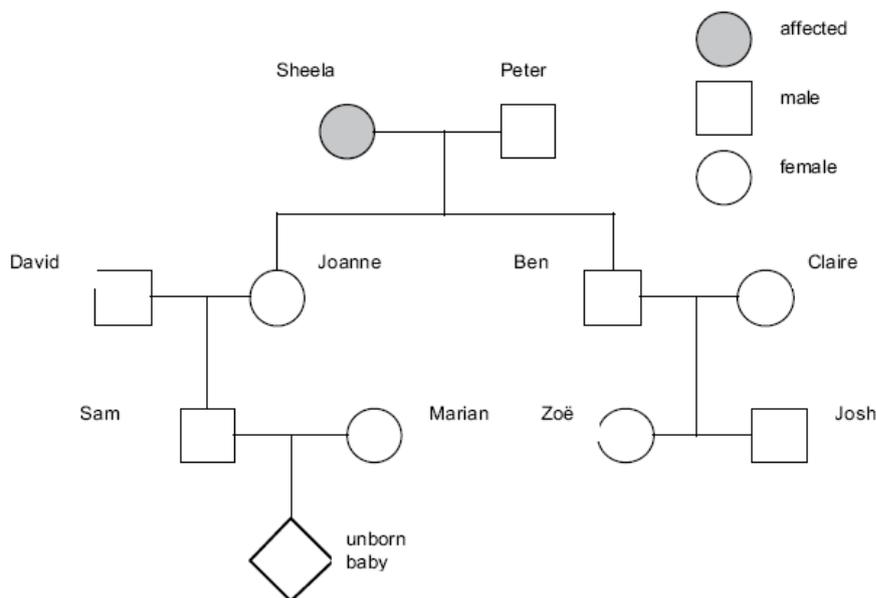
Huntington's disease

This is a genuine story with changed names.

An elderly lady, Sheela, goes to hospital having fallen in the street. After various tests Huntington's is diagnosed.

Figure 1 shows Sheela's family tree.

Figure 1



Use information from the textbook p 82-83 to find out the symptoms of Huntington's disease and how it is inherited; then consider what answers you would give to the following questions. Give reasons for the choices you have made, these should include ethical principles where relevant.

- 1) Which individuals in the family tree may have inherited Huntington's?
- 2) Joanne is about to become a grandmother for the first time. Should she find out if she has the disease?
- 3) Should she tell her son a) that she is having the test b) the result of the test if it is positive, or if negative?
- 4) Should Sam and Marian ask for genetic testing for their unborn baby?
- 5) What should they do if the test results are positive for Huntington's disease?