Scottish Huntington's Association

Specialist support for Huntington's disease families

What is Huntington's disease?

Huntington's disease (HD) is an inherited, degenerative neurological condition with symptoms that develop over time. As HD progresses it affects a person's movement (or motor skills), thinking processes (or cognition) and mental health.

There is currently no cure for Huntington's disease, however there is lots of support available to help you to live well despite the challenges of the disease.

1. What causes Huntington's disease?

Huntington's disease is caused by a 'spelling mistake' in the gene that tells our cells how to make a protein called huntingtin. This protein is very important in helping our brain cells to work properly.

What is a gene?

A gene is a section of genetic material (DNA) that gives our cells the recipe to make a particular protein. Each cell has two copies of every gene – we get one copy from our mother and the other from our father.

What happens if I have a faulty copy of the HD gene?

When one of our copies of the HD gene contains a 'spelling mistake', this means that our cells produce a misshapen form of the huntingtin protein which does not work very well. Over time, it builds up in our brain cells and eventually causes some of them to die. This cell death leads to the symptoms that we see in Huntington's disease.

What is my CAG repeat length?

You may have heard about a number called your CAG repeat length. This

number refers to how long the 'spelling mistake' in your faulty copy of the HD gene is. In all of us, we have a section in our HD gene where the letters "C-A-G" are repeated a number of times. "C-A-G" tells the cell that a particular building block needs to be added to this part of the huntingtin protein. If you have Huntington's disease, then you have too many of these "C-A-G" repeats in one of the copies of your HD gene. This means that too many building blocks are added to part of the protein and it comes out much too long. This stops it functioning properly. If you have 40 or more of these repeats, we know that you will definitely develop Huntington's disease if you live long enough.

2. How do you get Huntington's disease?

If you have Huntington's disease, it is very likely that one of your parents has or had the condition. Each person with an affected parent has a 50% chance of having inherited it from them.

In rare cases, you may find that you are the first person in your family to have Huntington's disease. This could be because your affected parent died before they showed symptoms, because you were adopted, or because the 'spelling mistake' in your HD gene has occurred for the first time in you.

The disease typically begins in mid-life, however a minority of people develop symptoms when they are younger. Other people may not experience symptoms until they are much older.

3. What are the symptoms of Huntington's disease?

Huntington's disease affects everyone differently, and your symptoms may be unlike those experienced by others in your family. There are three broad groups of symptoms:

Movement (or motor skills)

Many people with Huntington's disease experience involuntary movements

and issues with mobility. You can find out more about these and ways you can access support our Mobility factsheet.

Thinking processes (or cognition)

It might become more difficult for you to remember things and stay organised. It can help to use a whiteboard or diary to stay on top of things. You may also need assistance with certain tasks such as managing your finances. It is a good idea to appoint a Power of Attorney help you or to manage your money on your behalf. See our Planning For The Future factsheet to find out more about this.

Mental health

Huntington's disease can affect your mental health. Some people find themselves feeling low, anxious or irritable. Less often people experience more severe problems with their mental health. Our Mental Health factsheet will help you to find out about what support is available.

4. Can I get tested for Huntington's disease?

It is possible to have a predictive blood test if you are over 18 and known to be at risk of Huntington's disease. The result will tell you whether or not you will develop the condition at some point in the future. While some people take the test so they can prepare for the future, many people feel that being tested is not right for them. It a very personal decision and one that requires careful consideration. Before the test you will have counselling with a specialist Genetic Counsellor. They will help you to understand all the implications of having the test and the ways that either a positive or negative result could impact your life. If you are thinking about being tested, speak to your HD Specialist or GP for more information.

Useful links

Visit Scotgen.org for information about counselling and genetic testing.

Contact a Scottish Huntington's Association HD Specialist

Scottish Huntington's Association Youth Service

National and Regional Care Frameworks for Huntington's disease

Scottish Huntington's Association Financial Wellbeing Service

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