

# Pre-symptomatic testing for Huntington's Disease

Information for patients

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## Testing for the Huntington's Disease gene (HD)

You have been referred because of your family history of Huntington's disease.

This leaflet outlines what to expect from your appointments and explains the process for pre-symptomatic genetic testing for Huntington's disease (HD). A pre-symptomatic genetic test predicts whether a person with a family history of Huntington's disease, will develop the disease themselves.

**The testing process is usually carried out over a series of appointments.**

## Introductory appointment

At the first appointment you will meet with a member of the Clinical Genetics team. You will usually see this person at each appointment. We have a dedicated Clinical Psychologist to provide extra support with the testing process, if needed.

**Please note that no genetic testing will be done at your first appointment.**

We will ask about your family history of Huntington's disease to ensure that we are testing for the right condition and will discuss:

- the signs and symptoms of Huntington's disease
- how it is passed on through families
- what your chances are of inheriting a disease-causing Huntington gene
- how the test works and its limitations
- the effect a "good news" or "bad news" result may have on you and your family.

If you still wish to proceed, you can make another appointment, usually at least a month later.

Some people decide that they do not wish to go ahead. You are free to stop at any time during the testing process.

## Subsequent appointments

The aim of these appointments is to look at the advantages and disadvantages of knowing whether or not you are going to develop Huntington's disease. Once we have given you the result you can never go back, so it is important that you are sure that you want to know before you have the test.

After these appointments, if you decide that you want to proceed, then you can give a blood sample. The result is usually available two weeks after the sample is taken.

## Result appointment

This appointment is to give you the result of your genetic test. You will have planned with our team member how you will receive your result, and what support you may need. We encourage you to have someone with you who can offer you support.

We understand that this process may seem long. Please be assured that it is the result of research and discussion with other people who have already been tested.

You do not have to convince us to test you. It is your decision whether to have the test. We are here to provide information, to help you think through the issues involved and to provide support.

**This process is a guide and if you require more appointments over a longer period of time, we would be able to arrange this.**

If you would like more information, you are welcome to contact:

### **South East Scotland Clinical Genetic Services**

Western General Hospital, Edinburgh, EH4 2XU

Tel: 0131 537 1116

(we cover the Borders, Lothian and South West Fife)

### **Scottish Huntington's Association**

Phone: 0141 848 0308

Email: [sha-admin@hdscotland.org](mailto:sha-admin@hdscotland.org)

For more info: [www.hdscotland.org](http://www.hdscotland.org)

