

For more information:

If you need more advice about any aspect of the presymptomatic testing procedure for Huntington disease, you are welcome to contact:

Clinical Genetics Departments

Northern Scotland (main base Aberdeen)

Tel: 01224 552120 Fax: 01224 559390

(Aberdeenshire, Moray, Highland, Western & Northern Isles)

Tayside (main base Dundee)

Tel: 01382 632035 Fax: 01382 645731

(Perth & Kinross, Angus, North East Fife)

South East Scotland (main base Edinburgh)

Tel: 0131 651 1012 Fax: 0131 651 1013

(Borders, Lothian, South West Fife)

West of Scotland (main base Glasgow)

Tel: 0141 201 0808 Fax: 0141 201 0361

(Glasgow, Argyll & Bute, Ayrshire, Dumfries & Galloway, Stirling, Lanarkshire, Falkirk)

Further information and support is available from:

Scottish Huntington's Association (Scottish HA)

Thistle House, 61 Main Road. Elderslie. PA5 9BA

Tel: 01505 322245

email: sha-admin@hdscotland.nhs.uk

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Presymptomatic Testing Procedure for Huntington Disease



Testing for the Huntington disease gene

This leaflet has been designed to explain how this department approaches "presymptomatic" testing for Huntington disease. A presymptomatic test predicts whether or not a person, who has a family history of Huntington disease, will actually go on to develop the disease themselves.

The introductory appointment

The first appointment you receive will be an "introductory" appointment with one member of the Clinical Genetics team. This appointment is to enable us to meet you, and to exchange information.

No testing will be done at this appointment.

We need to know about your family history of Huntington disease so that, wherever possible, we can ensure that we are testing for the right condition. It also gives us the chance to explain the symptoms and signs of Huntington disease, how it is passed on through families, and what your chances are of having the Huntington gene. We also need to find out whether doing a test on you could affect other members of your family.

We will explain the test to you, how it works, and what its limits are. We will discuss the effect a "good news" or "bad news" result may have on you and your family.

If you still wish to be tested, we will make an appointment for you to begin the formal testing programme. Some people, however, decide that they do not wish to go ahead and have the test at this time. You are free to stop at any time during the testing programme, should you want to.

The programme for presymptomatic [predictive] testing

The programme for presymptomatic testing was developed with the help of the Huntington Disease Association (see back page for contact details), and is used by genetic centres throughout the United Kingdom.

The programme has come about by talking to those people who have been tested as well as those who are doing the testing, in order to avoid some of the problems which have arisen in the past.

We make every effort to ensure that you will see the same people throughout the testing programme.

What does the test involve?

1st pre-test appointment

This appointment takes place with two members of the clinical team, usually including the person that you have already met. We welcome and encourage you to bring someone with you for help and support.

No test is done at this appointment.

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

There is a three month gap before the next appointment which gives you time to think and talk through the issues raised. You may also have practical things which will need to be sorted out before your test (such as life insurance). These issues will be discussed in detail at this session.

2nd pre-test appointment

This appointment gives you the chance to talk through any matters which may have arisen since the first appointment. If, at the end of this appointment, you decide that you want to have the test done, then we will take the blood sample.

The three weeks wait after the blood sample is taken is the amount of time the laboratory here needs to do the test.

The result appointment

This appointment is to give you the result of the test in person. We never give out these results over the telephone or in a letter.

The staff involved in your appointments will not know the result of your test until shortly before you do. We do this so that you can telephone us at any time before the result appointment without worrying that we know something, but are not telling you.

We understand that this process may seem very long, but we have tried to make sure that we meet the needs of most people. This programme is the result of much discussion with people who have already been tested and with staff involved in the testing.

You do not have to convince us to test you

It is your decision whether or not to have the test. We are here to give you information to help you think through the issues involved, and to give you help and support.

Once again, you can withdraw from the programme at any time.