

Predictive Testing for the Huntington's Disease Gene

Information Guide

Introduction

This leaflet has been designed to explain the steps involved in having a predictive test for Huntington's Disease (also known as HD). A predictive test provides information about whether or not a person who has a family history of HD will go on to develop the disease themselves.

As the individual does not have the symptoms themselves, this type of test is sometimes referred to as a pre-symptomatic test.

Introductory genetic counselling appointment

The first appointment you receive will be an 'introductory appointment' with one of the members of the genetics team. This appointment is to enable us to meet you and exchange information.

No testing will be done at this appointment.

We need to know about your family history of HD so that, wherever possible, we can ensure we are testing for the right condition. It also gives us the opportunity to explain the signs and symptoms of HD, how it is passed on in families and what your chances are of having the Huntington's gene.

We will explain the test to you, how it works and what the limitations are. There will also be the chance to talk about the effect a 'good news' or 'bad news' result might 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. However, some people decide after their initial appointment that they do not want to go any further with testing at this time. You are free to stop at any time during the testing programme, should you want to.

The protocol for predictive testing

The predictive test protocol was developed with the help of the Huntington's Disease Association, who provide support to individuals and families affected by HD. A list of some of the information leaflets they produce and their contact details are near the end of this leaflet if you wish to contact them.

The testing protocol involves at least three appointments, but it is important that you take as long as you need before deciding to go further with testing. You are able to withdraw from the testing protocol at any time.

We understand that this process may seem very long, but it is based on the experiences of people who have been through predictive testing in the past and the things they have found most helpful.

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 before making your decision and to help you prepare for the result if you decide to be tested.

First pre-test appointment

This appointment takes place with a member of the clinical genetics team, usually the person that you have already met. We welcome and encourage you to bring someone along to this appointment who can be there to help and support you.

No testing will be done at this appointment.

The aim of this appointment is to look at the advantages and disadvantages of knowing for certain whether you are going to develop symptoms of HD. Once we have given you the test results you can never go back so it is important that you are clear that you want to know before we test you.

The sort of issues we consider at this appointment are practical things like the impact of having the test on your working life or if there are financial implications of having the test. You will also have the opportunity to discuss the emotional impact of having the test and to consider the way a result might affect family relationships or how having a test might affect the way you feel about the future.

Following this appointment, we would wait for you to contact us before arranging any further appointments.

Second pre-test appointment

This appointment gives you the chance to talk through any matters that may have changed or arisen since your last appointment and if you wish to go ahead with the testing, a blood sample will be taken at this appointment. A brief medical examination is also carried out before the blood sample is taken.

The results of the test take around three weeks to arrive and we will arrange your results appointment when the blood sample is taken.

The results appointment

This appointment is to give you the results of the test in person. We never give results over the phone or in a letter and we ask that you bring someone with you when you come for your results.

The staff involved in your appointment will not know the results of your test until shortly before you do. This is so that you can telephone us at any time without worrying that we know something and are not telling you.

For additional information or support

If you have any further questions about any aspect of Huntington's Disease, please contact:

Genetic Medicine

6th Floor, St Mary's Hospital, Oxford Road, Manchester M13 9WL

Telephone 0161 276 6506

Fax 0161 276 6145

Department staffed Monday–Friday, 9.00am to 5.00pm.

The Huntington's Disease Association produces a range of information leaflets, some of which are listed below:

- General information about Huntington's Disease
- Advice on life assurance, pensions and mortgages
- Information for teenagers
- Talking to children about Huntington's Disease

Leaflets and other information can be obtained by contacting the association at:

The Huntington's Disease Association (HDA)

Down Stream Building, 1 London Bridge, London, SE1 9BG

Telephone 0207 022 1950

Fax 0207 022 1953

Website www.hda.org.uk

Email info@hda.org.uk

Do you have difficulty speaking or understanding English ?

আপনি কি ইংরেজীতে বুঝতে কিংবা বুঝাতে পেরেছেন ? (BENGALI)

क्या आपको अंग्रेजी बोलने या समझने में कठिनाई है ? (HINDI)

તમે ભાષા કારણે વાતચીત કરવામાં મુશ્કેલી આવે છે ? (GUJARATI)

ਕਿ ਤੁਹਾਨੂੰ ਅੰਗ੍ਰੇਜ਼ੀ ਬੋਲਣ ਜਾਂ ਸਮਝਣ ਵਿਚ ਦਿੱਕਤ ਹੈ ? (PUNJABI)

Miyey ku adagtahay inaad ku hadasho Ingriisida aad sahamto (SOMALI)

هل لديك مشاكل في فهم اوالتكلم باللغة الانجليزية ؟ (ARABIC)

你有困難講英語或明白英語嗎？ (CANTONESE)

کیا آپکو انگریزی سمجھنے اور سمجھانے میں دقت پیش آتی ہے؟ (URDU)

Telephone 0161 276 6202 / 6342

Please let us know if you would like this leaflet in another format (e.g. large print, Braille, audio, British Sign Language video/DVD) or in another language.