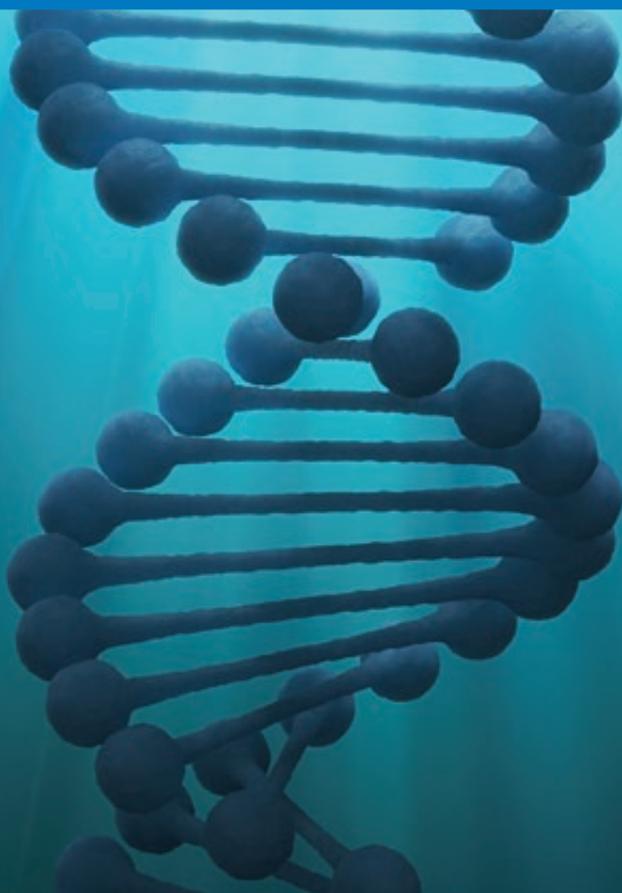


Presymptomatic testing for the Huntington disease gene

Information for patients



This leaflet explains how our department approaches presymptomatic testing for Huntington disease (HD). A presymptomatic test predicts whether or not a person who has a family history of HD will actually go on to develop the disease.

The programme for presymptomatic (predictive) testing

The programme for presymptomatic testing was developed with the help of the Huntington's 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 do the testing, to avoid some of the problems that have arisen in the past. We make every effort to ensure that you will see the same people throughout the testing programme.

The introductory appointment

At your first appointment you will meet one member of the clinical genetics team. No testing will be done at this appointment. We need to know about your family history of HD so that, wherever possible, we can make sure that we are testing for the right condition. It also gives us the chance to explain the symptoms and signs of HD, how it's passed on through families, and what your chances are of having inherited the HD gene.

We also need to find out whether doing a test for 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 and some of the issues you should consider before having a test.

There is a gap of, typically, one to three months before the next appointment, which gives you time to think and talk through the issues raised. You may also have practical things to arrange before your test, such as life insurance. Some people decide not to go ahead and have the test at this time. You are free to stop at any time during the testing programme.

Second pre-test appointment

This appointment may take place with one or two members of the clinical team, usually including the person 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 HD. 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.

Third pre-test appointment

This appointment gives you the chance to talk through any matters that may have arisen since the last appointment. If at the end of this appointment, you decide that you want to have the test, then we will take the blood sample. The three to four week wait for the results 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 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 long, but we have tried to make sure we meet the needs of most people.

You do not have to convince us to test you

It's your decision whether or not to have the test. We're here to give you information to help you think through the issues involved, and give you help and support. You can withdraw from the process at any time, even after the blood sample has been taken.

Useful contacts

● Huntington's Disease Association (HDA)

Suite 24, Liverpool Science Park, Innovation Centre 1,
131 Mount Pleasant, Liverpool L3 5TF

Tel: **0151 331 5444**

Email: **info@hda.org.uk**

Website: **www.hda.org.uk**

This booklet was written by:

Wessex Clinical Genetics Service
Princess Anne Hospital
Coxford Road
Southampton
SO16 5YA

Telephone: **023 8120 6170**

Website: **www.uhs.nhs.uk/genetics**

**If you need a translation of this document,
an interpreter or a version in large print,
Braille or on audiotape, please telephone
023 8120 4688 for help.**

www.uhs.nhs.uk/genetics

© 2016 University Hospital Southampton NHS Foundation Trust. All rights reserved.
Not to be reproduced in whole or in part without the permission of the copyright holder.

Version 4. Published May 2016. Due for review May 2019. GEN013.01