

## **Predictive testing for Huntington's Disease Information Leaflet**

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### **Testing for the Huntington's Disease gene**

This leaflet will explain how our department approaches predictive testing for Huntington's disease. A predictive test is a test which predicts whether or not a person, who has a family history of Huntington's disease, but has no symptoms themselves, will actually go on to develop the disease in the future.

### **The process for predictive testing**

The process for predictive testing was developed with the help of the Huntington's Disease Association (see below for contact details), and is used by genetic centres throughout the United Kingdom. It involves a series of appointments.

At your appointments you will meet with two members of the clinical team. We make every effort to ensure that you will see the same members of clinical staff at all of your appointments. We welcome and encourage you to bring someone with you for help and support.

### **What does it involve?**

#### **1<sup>st</sup> pre-test appointment**

#### **No testing is done at this appointment**

We need to know about your family history of Huntington's 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 signs and symptoms of Huntington's disease, how it is passed on through families, and what your chances are of having the faulty Huntington's gene. We also need to discuss whether doing a test on you could have implications for other members of your family.

We will explain the test to you, how it works, and what the limitations 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 arrange a further appointment for you. 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.

#### **2<sup>nd</sup> pre-test 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's 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 will be an agreed time period 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.

## The test appointment

This appointment gives you the chance to talk through any matters which may have arisen. If you decide you want to have the test done, then we usually offer to take the blood sample. It takes 4-6 weeks from the blood sample being taken, for the laboratory to process the test and issue a result.

## 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 date of your result appointment will be agreed with you in advance.

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 it is the result of much discussion with people who have already been tested and with staff involved in the testing process.

### **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 testing process at any time.

## For more information:

**If you need more advice about any aspect of the predictive testing process for Huntington's disease, you are welcome to contact:**

Liverpool Centre for Genomic Medicine  
Liverpool Women's Hospital NHS Foundation Trust  
Crown Street  
Liverpool  
L8 7SS  
Telephone: 0151 802 5001 or 5008      Email: [lwft.clingen@nhs.net](mailto:lwft.clingen@nhs.net)

Further information and support is available from Huntington's Disease Association

Huntington's Disease Association  
Suite 24, Liverpool Science Park  
Innovation centre 1  
131 Mount Pleasant  
Liverpool  
L3 5TF  
Telephone 0151 331 5444  
Fax 0151 331 5441  
Email [info@hda.org.uk](mailto:info@hda.org.uk)  
Website [www.hda.org.uk](http://www.hda.org.uk)



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This leaflet can be made available in different formats on request. If you would like to make any suggestions or comments about the content of this leaflet, then please contact the Patient Experience Team on 0151 702 4353 or by email at [pals@lwh.nhs.uk](mailto:pals@lwh.nhs.uk)

Liverpool Women's NHS Foundation Trust  
Crown Street  
Liverpool  
L8 7SS  
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