for HD and are concerned about symptoms developing we can arrange for you to see the relevant specialists. Research opportunities can also be discussed.

The programme for predictive (pre-symptomatic) testing
The programme for pre-symptomatic testing was developed with the help of the Huntington’s Disease Association and is used by genetic centres throughout the UK.

All of these genetics centres follow the same guidelines and allow plenty of time for the implications of testing to be considered and discussed. This process has been developed to help ensure that only people who are certain that they want to be tested go through with testing.

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 a test is carried out and are prepared for any outcome.

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.

More information
Huntington’s Disease Association (HDA)
Tel: 0151 331 5444
Email: info@hda.org.uk
www.hda.org.uk

Huntington's Disease Youth Organisation (HDYO)
www.hdyo.org.uk

HDBuzz – Huntington’s disease research news in plain language.
http://en.hdbuzz.net/

Or contact your local Clinical Genetics Service.

Feedback
We appreciate and encourage feedback. If you need advice or are concerned about any aspect of care or treatment please speak to a member of staff or contact the Patient Advice and Liaison Service (PALS):

Freephone: 0800 183 0204
From a mobile or abroad: 0115 924 9924 ext 65412 or 62301
E-mail: pals@nuh.nhs.uk
Letter: NUH NHS Trust, c/o PALS, Freepost NEA 14614, Nottingham NG7 1BR
www.nuh.nhs.uk

Pre-symptomatic (predictive) testing for Huntington’s disease (HD)  
Information for patients

Clinical Genetics

This document can be provided in different languages and formats. For more information please contact:

Clinical Genetics Service
City Hospital
The Gables, Gate 3
Hucknall Road
Nottingham NG5 1PB

Tel: 0115 962 7728
Email: nuhnt.clinicalgenetics@nhs.net
This leaflet has been designed to help explain how our department approaches ‘pre-symptomatic’ testing for Huntington’s disease (HD).

A pre-symptomatic test predicts whether or not a person who has a family history of HD will actually go on to develop the disease themselves.

The first appointment
Your first appointment will be an introductory appointment with one or two members of the clinical genetics team.

There is a lot to consider when facing a pre-symptomatic test and we encourage you to bring a close friend or relative along with you for support.

This appointment is to enable us to meet you and exchange information. It gives you the chance to find out about all the testing options available.

We need to talk about your family history of HD so that wherever possible, we can ensure that we are testing for the right condition. It also gives us the chance to discuss the signs and symptoms of HD, how it is passed on through families and what your chances are of having the Huntington’s gene expansion.

We will talk about how the test is performed and the type of results that can be received as well as the test limitations.

We will also begin to explore the impact that having a test may have on you and other members of your family and decisions you may make in the future.

After this appointment you will receive a detailed summary letter. If you still wish to be tested or to discuss it further, another appointment can be arranged. Some people decide that they do not wish to go ahead and have the test at this time. You are free to opt out of the testing process at any point you choose.

No testing will be available at this appointment.

Further appointments
A further appointment(s) are arranged with a few weeks between them to allow space for practical issues to be addressed, and time for you to think about the information discussed.

You will be encouraged to think about why you want to have the test and what the result may mean for you in emotional and practical terms. We will discuss how you may cope with your results. You would also need to think about the implications of your result for others close to you.

We will discuss with you the possible impact of genetic testing on your employment and insurance. There will be the option for you to be examined by a genetics doctor or neurologist for signs of HD if you wish.

After these discussions, if you still want to be tested, a blood sample can be taken at a third appointment (at the earliest). The results will then take around four weeks.

The results appointment
This appointment is to give you the result of the test in person. It is not our usual practice to 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 that we are not telling you.

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

Follow up appointment
Follow up will be negotiated between you and your genetic counsellor. Usually you will be telephoned by the counsellor a week or two after your results.

Some people like to come back to the clinic to talk to their genetic counsellor regardless of the result, others prefer not to. About 3-6 months after your results you will be sent an appointment to come to clinic.

This will be an opportunity to check how you and your family are adapting to the news. Ongoing follow-up arrangements will be discussed further.

If you have inherited the gene expansion