

Predictive testing for an inherited degenerative condition

This leaflet gives more information about predictive testing, including things you should think about and how the results may affect you.

Introduction

The decision about whether or not to have testing for inherited degenerative conditions is a very complicated and personal one. Many people choose not to be tested. For other people, the test gives information about their future. There are no right or wrong choices, but it is important that you think carefully about being tested and make an informed choice.

This leaflet is for people who have met with a clinical geneticist or genetic counsellor for an initial discussion. It is meant to help you to think about some of the issues involved in testing, and in dealing with the test results.

Your relationships

Relationships with spouse or significant other

Is this person supportive of your decision to be tested, or do they have concerns about your decision or how you have come to it? Have you discussed issues that affect you as a couple, that might change depending on your test results? For example, decisions about having children, retirement and long-term care issues? Many people who are at risk for a degenerative condition are concerned that they might be left on their own by their partner if they develop symptoms. Have you discussed this or other fears with your partner?

Relationships with extended family

How do you think your results will affect your interactions with your brothers and sisters, your parents and extended family? If the results show that you have inherited the gene alteration, will this affect how you feel about your affected relatives. For example, feeling closer to, or more distant from, them?

If you do not have the gene alteration you may experience 'survivor guilt'. This is when you may wonder why you have 'escaped' the disease when other family members have been less fortunate. A person given a normal (negative) result may also experience a new feeling of responsibility for affected family members.

Who, if anyone, in your family do you plan on telling about your results? How will you tell each of them – by phone, letter, at a family meeting?

Relationships with children

Do your children know about the condition? Are they pushing you to have the testing, or are you involving them in your decision making? Will you tell them your results? If so, how will you tell them?

Relationships with friends

Are there people in your life that you feel you can talk to about the condition and about your decision regarding testing? Have you been through difficult times in your life with them before? In what ways were they supportive to you?

Having children

Knowing that you are at risk may affect your decisions about having children yourself. Some people decide never to have children at all, while others go ahead on the grounds that the children are likely to have many years of normal life before developing the disease (if they inherit it at all).

Couples at risk of degenerative disease are not usually allowed to adopt, although they may be able to undertake fostering. Egg donation and artificial insemination by donor (AID) may also be considered.

If you do have the faulty gene, your unborn children can be tested to see if they have inherited it. This can be done either through prenatal testing or through pre-implantation genetic diagnosis (PGD). These options should be discussed with your local genetics service.

Careers and telling people at work

Will your results affect your decision about the type of work you are doing now or plan to do in the future? Do you plan to tell the people you work with about your decision to be tested or the test results?

Many people at risk for these conditions fear they will be treated differently at work if they tell people about the condition. Some people fear that they will not be considered for promotion, or that they may even lose their jobs. Some companies have confidential employee services where you can discuss these concerns.

Thinking you have the disease

Honestly considering your feelings about whether or not you believe you have or will develop this neurological condition is important. It can be more difficult to deal with the test results if the results are the opposite of your inner feelings.

Assessing your own coping strategies

How have you dealt with difficult situations in the past? What things do you do to get you out of a slump? For example, call a friend or family member, go for a walk, exercise, work in the garden?

What strategies work well to help you out in the short term? Are they different to those that work over the longer term? How do you ask for help when you need it?

Recognising what resources worked for you in the past is helpful because you can start doing them again when you need help in the future.

How do you deal with uncertainty?

For many people, one of the reasons for having a test is because they do not wish to live with the uncertainty of not knowing.

For most inherited degenerative conditions, having a predictive test will tell you whether or not you are at risk of developing symptoms. It will not tell you for definite whether you will develop symptoms, what exactly those symptoms might be or at what age they are likely to occur. It is important to be realistic about the uncertainty which you may feel if the result confirms you have inherited the altered gene.

Timing of testing for the disease

The process of being tested for an inherited degenerative condition, and dealing with the results will be stressful and is often disruptive to dealing with everyday problems.

It is good to choose a time to be tested when complicating factors from the outside are at a minimum. For example, being in the middle of the break-up of a relationship, or during a stressful time at school or work is not a good time to be tested.

Testing at a time of celebration may also not be a good idea. For example, directly before or after marriage, or in the middle of important holidays.

Insurance and financial planning

The Code on Genetic Testing and Insurance is reviewed every three years. Currently, insurance companies can only ask you for the result if the genetic test is for Huntington's disease and if you are taking out more than £500,000 of life insurance. But you may have to declare a family history when you take out insurance. You can ask your GP not to send your insurance company any information about predictive genetic test results unless you want the insurance company to take into account a result that is in your favour. For further information, please visit the website for the Association of British Insurers, [w: www.abi.org.uk](http://www.abi.org.uk).

For more information

It is important that you think carefully about having predictive testing and make an informed choice.

If you wish to continue with the predictive testing, our current process is as follows:

- You must have at least two pre-testing face-to-face sessions.
- The results must be given to you in person.
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We do advise that you have someone to support you at all clinical sessions.

Please contact your local genetics clinic as details may be different in your region.

Contact us

For patients in South East Thames region: Clinical Genetics Department, 7th Floor, Borough Wing, Guy's Hospital, Great Maze Pond, London, SE1 9RT, **t:** 020 7188 1364, **f:** 020 7188 1369, **w:** www.guysandstthomas.nhs.uk/genetics

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline. **t:** 020 7188 8748, Monday to Friday, 9am-5pm

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