

How do you go about having the test?

- Each member of the family who wishes to discuss having the test would need to be referred to their local genetics centre by their GP.
- If you are considering having the test, you may find it helpful to bring someone (partner, friend or family) to the appointment along with you, for support.
- Experience throughout the United Kingdom has shown that having a series of discussion sessions at the genetics clinic gives people, who are considering a genetic test, time to think about the issues in detail.
- If you are thinking about having this kind of genetic test, you would be offered a minimum of two appointments at the genetics clinic. The appointments would be some time apart to give you time to reflect on the discussion and to make sure it is the right decision for you.
- After these appointments, if you wish to have the test you will be asked to read and sign a consent form. A small blood sample will then be taken.
- Once the blood is taken, the laboratory staff would test the sample to find out whether or not you have inherited the altered gene.

You can change your mind and decide not to have the test at any time before the result is given.

- We will arrange another appointment for you 4 to 6 weeks after your blood is taken. At that appointment we will give you the result in the clinic.
- After receiving the results, you will be offered further appointments whether or not you have inherited the altered gene.

For more information:

If you need more advice about any aspect of inherited cancer, you are welcome to contact:

Clinical Genetics Departments

Northern Scotland (main base Aberdeen)
Tel: 01224 552120 Fax: 01224 559390
(Aberdeenshire, Moray, Highland, Western & Northern Isles)

Tayside (main base Dundee)
Tel: 01382 632035 Fax: 01382 645731
(Perth & Kinross, Angus, North East Fife)

South East Scotland (main base Edinburgh)
Tel: 0131 651 1012 Fax: 0131 651 1013
(Borders, Lothian, South West Fife)

West of Scotland (main base Glasgow)
Tel: 0141 201 0808 Fax: 0141 201 0361
(Glasgow, Argyll & Bute, Argyshire, Dumfries & Galloway, Stirling, Lanarkshire, Falkirk)

If you need more advice about cancer and support groups, please contact:

Maggies Centres

www.maggiescentres.org

Maggies Highlands Tel: 01463 706302

Maggies Dundee Tel: 01382 496384

Maggies Edinburgh Tel: 0131 5373131

Maggies Glasgow Tel: 0141 330 3311

Seen in clinic by.....

This leaflet was originally designed by Clinical Genetics, Guy's Hospital. Updated by Genetic Interest Group Scotland. Last updated May 2003.

Genetic Testing for Inherited Cancer



Information for families
where an altered cancer
gene has been found

What are the issues to think about when deciding whether or not to have a gene test?

A genetic test can establish whether you have an alteration in a gene which could affect your health.

It can be difficult to make a decision about whether or not to have a genetic test. This leaflet explains about some of the issues that you may wish to consider.

We all have gene alterations. Many of these do not affect our health. It is still quite unusual for a person to know they have an alteration in a specific gene.

There are reasons for and against having a genetic test. Within one family, relatives often have different views. You should try to make your own decision, without feeling pressured from relatives or other influences.

You will have plenty of opportunity to talk through the issues surrounding the test with the genetic counsellor or doctor.

How do you think you would cope if the test were to show that you have inherited the altered gene?

For some people, knowing that they have the altered gene is preferable to living with uncertainty. Having a genetic test enables them to make decisions about the future and about screening and measures to reduce their risk.

Other people may prefer not to have the test because they may feel very anxious if the test shows that they have the altered gene.

It is important that you think through how you would cope with a positive result before you have a genetic test.

How do you think you would cope if the test were to show that you have not inherited the altered gene?

Perhaps surprisingly, it can often take people some time to get used to the knowledge that they do **not** have the altered gene. This can be particularly difficult when other relatives have a different result.

People who do not have the altered gene have the same chance of developing cancer as other people in the general population.

If the test were to show that you have the altered gene, this would mean that your children would also be at risk of having the altered gene. How do you think you might feel about this?

Having a genetic test may be important to other people, such as your children. It will help them to understand their own risk and if necessary make choices about screening and risk reducing options.

It can be very difficult knowing that you could have passed on an altered gene to your children. This can be hard to deal with even if you know that you had no control over which genes you passed on.

If you were to have the test, would you want to tell anyone the test results?

It is important to think about who you would want to know about your test as it is very personal information. Many people who attend our clinic find that it helps to confide in a partner, trusted friend or relative.

Would having the test affect your ability to get life or medical insurance?

At present, if you have already obtained your insurance, having the test should not affect your current policies. However, it is not possible to know whether it will affect your ability to get or to change insurance policies in the future.

Would having the test affect your employment?

If the test shows you have the altered gene it would be your decision whether or not to inform your present employers. Some employers might ask about this if you apply for a new job.

It is important that each family member makes the decision that is best for them. We will support you whether you decide to have the test or whether you decide against having the test. It is your decision!