

What would a genetic test tell you?

A genetic test would tell you whether or not you have inherited an altered BRCA1 or BRCA2 gene (please see leaflet "Inherited Breast and Ovarian Cancer").

What does it mean if you are tested and find that you have inherited an altered BRCA1 or BRCA2 gene?

This would mean that your chance of developing breast cancer during your lifetime would be up to 80%.

Your chance of getting ovarian cancer during your lifetime would be up to 45%.

Each of your children (if you have any) would have a 50/50 chance of having inherited the altered gene from you.

What does it mean if you are tested and find that you have not inherited an altered BRCA1 or BRCA2 gene?

In this case your risk of getting breast and ovarian cancer during your lifetime would be the same as that for any other woman. Your children would not be at any increased risk of breast or ovarian cancer.

What can you do to help with early detection and prevention of breast and ovarian cancer?

Breast awareness: By being aware of how your breasts normally look and feel, you are more likely to notice if there are any changes in your breasts. If you are concerned, you can go along to your GP who will refer you to a specialist if necessary.

Breast/ovarian screening: If you are at increased risk of these types of cancer, you can be referred for breast and/or ovarian screening.

Risk-reducing surgery: Some women who are at very high risk of breast or ovarian cancer consider having surgery to remove their breasts, ovaries and fallopian tubes. Surgery does not completely remove the chance of developing cancer, although the risk of cancer is greatly reduced.

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, Ayrshire, Dumfries & Galloway, Stirling, Lanarkshire, Falkirk)

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

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, Guys Hospital. Last updated Mar 2002. Updated by Genetic Interest Group Scotland

Genetic Testing



Information for women
with a family history of
breast or ovarian cancer
who have not had cancer
themselves

What can we do at the Family Cancer Clinic?

From your family history, we can estimate how likely it is that some of the women in your family have inherited an increased tendency to develop breast or ovarian cancer.

We can also estimate your chance of getting these cancers during your lifetime and talk to you about your options for screening and reducing your risk. It **may** be possible for you to have a genetic test.

Who can have a genetic test?

If there is a strong chance that some of the women in your family have an inherited susceptibility to breast or ovarian cancer we will have talked to you about genetic testing.

Before we can even begin to think about testing you we first need to look at the BRCA1 and BRCA2 (breast/ovarian cancer genes) in a blood sample from your relative who has had breast or ovarian cancer.

A genetic test may be available for you, if there is a strong family history of breast or ovarian cancer and a relative who has had this type of cancer who is willing to give a blood sample for genetic testing.

In some families there is a lower chance of finding a genetic alteration. We may have talked to you about storing a blood sample from your relative who has had cancer for possible testing at some time in the future.

How does genetic testing affect the family?

Having a genetic test raises many issues both for relatives who have not had cancer and for relatives who have had cancer.

It is therefore important for anyone who is considering having a genetic test to have the opportunity to talk through the issues in order to help them to reach a decision about what they want to do.

What needs to happen before you can have a genetic test?

You would need to approach your relative who has had breast or ovarian cancer to see if she would consider giving a blood sample for genetic testing.

This is not always an easy question to ask and it is up to your relative to decide whether to give the blood or not.

We will give you a form for your relative to fill in if she is happy for us to have access to her medical records. On that form there will be a space for her to tell us if she is interested in talking about inherited cancer. If she is we will contact her and arrange to talk to her about genetic testing.

If your relative decides to give a blood sample, we can take the blood at the clinic.

The laboratory team will look for alterations in the genes that can cause breast and ovarian cancer (the BRCA1 and BRCA2 genes) in your relative's blood sample. We will contact your relative with any information as we receive it from the laboratory.

Any result will be confidential to your relative. It would be up to her to decide who she wishes to tell about it.

What would it mean for you if we do not find an altered gene in your relative's sample?

This would mean that you could not be tested at that time.

Unfortunately, if we do not find an altered gene in your relative's sample, her cancer may still have been inherited. She might have an alteration in another gene that has not yet been discovered. Alternatively, we were unable to find the alteration in the genes that we tested.

This could mean that you are still at increased risk of breast or ovarian cancer. In that case it would be important for you to continue with any screening that has been set up for you.

What would it mean for you if we do find an altered gene in your relative's sample?

This would mean that **you could be tested** to see if you have inherited the same altered gene.

Before you have a genetic test we would offer you the opportunity to come back to clinic. We would then discuss what genetic testing could mean for you and how you would feel if you were found to have the altered gene.

We would ask you to take some time to think about this and to come to another appointment with the same genetic counsellor a month or so later. At the next appointment, we could take a blood sample from you if you still wish us to.

We would ask you to come back to the clinic for your result four weeks later. After the result, we will see you as often as you would like. We can also arrange further support for you.