

Information about genetic testing for ovarian and breast cancer

This information leaflet is intended to help women with ovarian cancer understand some of the issues around genetic testing for BRCA1 and BRCA2 genes.

About genetic testing and me

All of us have BRCA1 and BRCA2 genes. Around 10% of women with certain types of ovarian cancer have a fault in their BRCA1 or BRCA2 gene. Faults in these genes increase the chance of developing ovarian and breast cancer and more rarely prostate and pancreatic cancer. Any woman diagnosed with high grade serous ovarian cancer under the age of 75 will be eligible for genetic testing regardless of any other family history. Women diagnosed with high grade serous ovarian cancer who are older than 75 may be eligible for genetic testing if they have a family history of ovarian or breast cancer.

1. Why should I consider genetic testing?

It can be very helpful to know if you have ovarian cancer as a consequence of a BRCA1 or BRCA2 gene abnormality. The information can help you and your oncologist decide whether you would benefit from a new drug called a PARP inhibitor. The information is also useful when discussing future treatments or participation in clinical trials. The results will also help you understand whether you are at risk of other cancers. Lastly, if you do have a BRCA gene fault, genetic testing can be offered to your relatives to find out if they are at increased risk of developing cancer.

2. How can I get tested?

We are now offering this testing for ovarian cancer patients in the out-patients clinic. You can discuss this with your oncologist or clinical nurse specialist (CNS).

If you decide to be tested we will take a blood sample for analysis and will inform you of the result.

3. If I decide to be tested how long will it take to get a result?

Usually it takes 4-8 weeks to get a result. It is useful to consider genetic testing soon after diagnosis so you and your oncologist can be informed as soon as possible about treatment options.

4. I'm worried about what I might find out. Are there any reasons I shouldn't be tested?

Having genetic testing is a big step, both personally and because of the implications it may have for your family. It is a personal decision, and your oncologist/CNS will help you understand the implications for you and your family, so that you can reach an informed decision about whether to have the test.



5. What if the test shows that I have a BRCA fault?

You will be referred to the genetics service for further discussion about the significance of your result. Your oncologist will discuss with you whether your result will alter your treatment options. We can take advantage of this genetic change by prescribing tablets, called PARP inhibitors, which can be used to delay the illness worsening.

6. What if no BRCA1 or BRCA2 fault is found?

This is the most likely outcome as most women with ovarian cancer do not have a BRCA1 or BRCA2 fault. This would be reassuring as you are unlikely to be at high risk of developing a different cancer in the future. Also, if no BRCA1 or BRCA2 fault was found we would not refer you or your family to the genetics service unless you had a strong family history of cancer.

7. Is the test result always clear cut?

In 95% of tests there is a definite 'no' or 'yes' answer. However in about 5% of tests, the result is something known as 'a variant of uncertain significance' (VUS). The vast majority - 99% of VUS are harmless and are not the cause of ovarian cancer and do not increase the risk of any other cancers.

8. What further information and help can I get?

At the end of this leaflet there are some websites that can give you further information about genetic testing and what it might mean for you and your family.

9. Will my information be confidential?

All data collected about you will be stored in secure files. The only people who will know your identity are the hospital staff and laboratory staff reporting your test results, who are bound by professional duty to protect your privacy.

About genetic testing and my family

1. If I have a BRCA gene fault what does this mean for my family?

If you are found to carry a BRCA gene fault then other people in the family (including your parents, siblings and/or children) may also carry it. You will be referred to the genetic service to discuss the implications for your relatives, including how they can access genetic testing.

2. How and when can I tell my family that they may be at increased risk of cancer?

This is a personal decision and we advise that you discuss this at your oncology appointment and with your partner/close friends. If you have children you will need to decide at what age to tell them. However, they will not be offered testing for a BRCA fault under the age of 18.

3. What should my family members do if they want to consider genetic testing?

They should ask their GP to refer them to their nearest genetics clinic. Finding that you have a BRCA gene fault can raise many issues, such as whether to opt for screening or risk-reducing surgery. It is important to explore these issues with a genetic counsellor before making a decision about considering testing family members. Your genetic test result will be needed so your relatives can be tested for the BRCA gene fault identified in you.

4. Will this affect my relatives taking out life or critical illness insurance?

There is currently an agreement in place which states that anyone who undergoes a predictive genetic test for breast or ovarian cancer is able to take out life and critical illness insurance without disclosing the results. This is called the Concordat and Moratorium on Genetics and Insurance. For the latest guidance or if you have any questions on this issue we recommend discussing these with the Association of British Insurers (www.abi.org.uk or tel: 0207 6003333).

Further information

BRCA Umbrella

www.brcaumbrella.ning.com

Breast Cancer Now

www.breastcancer.org.uk

Genetic Alliance UK

www.geneticalliance.org.uk

Ovacome

www.ovacome.org.uk

Ovarian Cancer Action

www.ovarian.org.uk

Target Ovarian Cancer

www.targetovariancancer.org.uk

This leaflet is based on information produced by Tracie Miles, lead gynae-oncology nurse specialist at Bath Hospital, with input from organisations who share the purpose of informing and supporting women affected by ovarian cancer.

Notes:

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact patient.information@christie.nhs.uk

For information and advice visit the cancer information centres at Withington, Oldham or Salford. Opening times can vary, please check before making a special journey.

Contact The Christie Hotline for
urgent support and specialist advice
The Christie Hotline: 0161 446 3658
Open 24 hours a day, 7 days a week

