

GENETIC TESTING FOR WOMEN AFFECTED BY OVARIAN CANCER

WHY HAVE I BEEN OFFERED A GENETIC TEST?

Around one in 70 women will be diagnosed with ovarian cancer during their lives. A small number of these women will have changes in their genetic makeup that has affected their risk of getting cancer. Finding out if you are one of these women may help in making the best choices for your current and future treatments.

It is important for you to know that the test can also give you information about your risk of developing other cancers. The results might also provide information about your relatives' risk of developing cancer.

THE TEST

The test is carried out on a blood sample and looks for changes in genes* known to be associated with ovarian cancer risk.

People who have specific changes in these genes have an increased risk of cancer; in particular ovarian cancer and sometimes other cancers.

Knowing about increased risk means that additional screening to detect the early signs of cancer may be available or there may be other steps to reduce the risk.

If you are found to have a change in one of these genes, there is a chance that other people in the family might have the same gene change.

THE RESULTS

Possible outcomes of genetic testing:

- No gene change identified: In most people the test will NOT find a gene change.
 This reduces the chance of a predisposing gene being responsible for your cancer.
- "Pathogenic" or "Likely Pathogenic" (disease-causing) gene change identified:
 This confirms an inherited risk and may help in making decisions about your treatment. It may also confirm that your risk of another cancer is increased.

 Because we share genes with our relatives, there is a chance they may have an increased risk of cancer too. It would be possible for them to have a genetic test.
- "Variant that needs further assessment": We all carry variations in our genetic code. The majority of these are NOT linked to disease. If testing identifies a variant which requires further assessment, this will be discussed with you.

WHAT HAPPENS AFTER MY RESULT?

The clinician who has arranged the test for you will give you your result, usually at your next routine visit. If your test finds a change in one of the genes, they will offer to refer you to the genetic clinic.

At the genetic clinic you will meet with a genetic clinician who will discuss your result with you and what it might mean for you and your relatives. There will be time to think about the best way forward for you and they can spend time answering any questions you might have.

It might be that you would like this appointment soon after your results or you may wish to wait a while. You can contact the genetic service directly or ask your hospital doctor or GP to refer you.

If any of your relatives would like to come along to the genetic clinic then they should request an appointment through their GP.

WHAT IF I WANT MORE INFORMATION ABOUT HAVING THE TEST?

If you would like more information, please speak with your clinician.

Also you can phone the duty genetic counsellor direct, at the number on this leaflet, who will be happy to go through any questions you may have or arrange an appointment to see you.

If your genetic test does not find any genetic changes but you have a family history of cancer, it is still possible that your relatives may have an increased risk of developing cancer. If you think this applies to you, you could talk to your GP or hospital clinician.

A limitation of any genetic test is that just like much of medical science, we cannot yet know with certainty all the factors that influence health. Very occasionally the current understanding of a gene change or variant may change as more information becomes available.

*Current ovarian cancer panel: BRCA1, BRCA2, BRIP1, MLH1, MSH2, MSH6, RAD51C, RAD51.

CONTACT DETAILS FOR THE GENETIC SERVICES

Duty Genetic Counsellor South East of Scotland Clinical Genetics Service, Molecular Medicine Centre Western General Hospital Crewe Road South Edinburgh, EH4 2XU

Tel: 0131 537 1116