South East Of Scotland Genetic Service
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NHS Lothian

BRCA1 or BRCA2 Predictive Testing Information Leaflet

A gene change has been identified in your family and is thought to be the cause of your family history of cancer. This means that a test is available for you, to see if you have inherited the gene change and have an increased risk of developing cancers. You will either be tested for **BRCA1** (BReast CAncer gene 1) or **BRCA2** (BReast CAncer gene 2) depending on which one has been identified in your family.

If you carry the gene change, your lifetime risk of cancer is significantly increased and your children or future children are at a 1 in 2 (50%) risk of inheriting the gene change.

If you do not carry the gene change, your risk of developing cancer is similar to other people in the general population and your children would not be at risk of inheriting the gene change.

If you are found to have the gene change, there are a number of ways you can manage your increased risk. These include screening, risk reducing surgery and chemo prevention. **Please see overleaf for more information.**

A limitation of any genetic test is that just like much of medical science, we do not 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.

Plan of action going forward

Please tick as appropriate		Enter details
	You have decided to proceed with testing; We have made the following arrangements for you to receive the results.	
	A follow up appointment has been arranged on	
	You have decided to get back in touch when you feel ready to proceed with testing.	

Following testing, results are usually available within 6 weeks. Results are confirmed in writing to you and copied to your referring clinician/GP.

You were seen by:	Genetic Counsellor	Patient Label
Date:		

The following management options are available if you have inherited the gene alteration. These *may* also be appropriate to consider should you decide not to proceed with genetic testing.

Females

Breast cancer

Screening - screening for women at a significantly increased risk of breast cancer is by a combination of mammography and MRI scanning. Current recommendations are:

- From 30 - 49 years: MRI every year
- From 50 - 69 years: Mammograms every year
- 70 years+: Mammograms every 3 years (through the National Breast Screening Program)

Tamoxifen and breast cancer risk reduction (BRCA2 only) - Research suggests that taking Tamoxifen tablets for 5 years reduces your risk of breast cancer by at least a third. Tamoxifen is a drug that blocks the effect of the female hormone oestrogen on breast tissue and slows down cell growth and division. It has been used for 40 years in the treatment of breast cancer.

Risk reducing breast surgery - Having your breasts removed reduces breast cancer risk by over 90%. There are many surgical options available that include reconstruction surgery. Breast surgeons suggest that surgery is considered from the late 20's onward for optimal results.

Be breast aware - We would encourage you to be breast aware and seek advice from your GP if you notice any changes in your breasts. An additional information leaflet has been supplied.

Ovarian cancer - Unfortunately there is no effective screening available for ovarian cancer.

Risk reducing ovarian (and fallopian tube) surgery - Having surgery to remove your ovaries and fallopian tubes has been proven to reduce the risk of ovarian cancer by over 90%. Ovarian cancer, even in families with a genetic predisposition, rarely occurs before age 40 years, so surgery is best considered between the ages of 35 and 40 years, for optimal benefit. The disadvantages of surgery include the small risks involved in the procedure itself but more importantly the implications of loss of fertility and the onset of the menopause.

Males

Breast cancer (men) - Men who have alterations in the BRCA1 or BRCA2 gene are not at high enough risk of breast cancer to need extra screening but if you had symptoms that you were concerned about you should go to your GP and ask their advice.

Prostate cancer (men) - Men who have changes in the BRCA2 gene have an increased risk of prostate cancer. For these individuals, preliminary findings in a research study suggest that there is merit in considering having regular PSA blood testing from around age 40 years. It is unclear at this time if it is helpful in men who have a BRCA1 gene change.

Additional Information

***Preimplantation Genetic Testing (PGT)* -** Some BRCA carriers (both female and male carriers) might consider the option of PGT to avoid passing on the BRCA gene to their children. PGT is a process that involves '*in vitro* fertilisation' (IVF) to create embryos from the couple in the laboratory, which are then tested at an early stage for the familial BRCA mutation.

***Insurance and genetic test results* -** In 2018 the Association of British Insurers agreed to an open-ended moratorium which means that you will not have to disclose the results of your predictive genetic test to them when you are taking out insurance. The Moratorium will be reviewed by the Department of Health and the ABI every 3 years. For further information please see:
www.abi.org.uk/data-and-resources/tools-and-resources/genetics/genetics-faqs/