



FACTSHEET



information on **living with breast cancer**

Hereditary Breast Cancer

This factsheet aims to give you information on breast cancer that runs in a family. This is called hereditary breast cancer. It describes what hereditary breast cancer is, how it is passed on, and the importance of family history in guiding the search for changes in genes that can lead to cancer. Even though this factsheet is mainly aimed at women, it may also be relevant to men.

HOW COMMON IS BREAST CANCER?

Breast cancer is now the second most common cancer in Ireland. It affects over 2,000 women in Ireland every year. It is less common in women under the age of 30 and occurs more often in women over the age of 50.

Men also develop breast cancer but this is very rare and about 15 men develop breast cancer each year in Ireland.

WHAT CAUSES BREAST CANCER?

The cause of breast cancer is still not fully known. A woman has a 1 in 12 lifetime chance of developing breast cancer but some women are at higher risk of developing the disease. Experts believe that between 5–10% of breast cancer cases are caused by changes that have been passed on in certain key genes.

WHAT ARE THE RISK FACTORS FOR BREAST CANCER?

There are some factors that increase a woman's risk of developing breast cancer over which we have no control.

These include:

- Being female
- Getting older
- Family history of breast or ovarian cancer
- Early menarche (starting your periods before the age of 12)

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- Late menopause (change of life after the age of 55)

Other factors that can slightly increase risk include:

- Being overweight
- Not being physically active
- Hormone Replacement Therapy (HRT)
- Contraceptive pill use
- A history of benign breast disease
- First pregnancy after age of 30
- Too much alcohol use
- Smoking tobacco

WHAT IS HEREDITARY BREAST CANCER?

Hereditary breast cancer occurs when a faulty gene is passed on from either parent. This greatly increases the likelihood that cancer will develop but people can carry such genes and not develop breast cancer. It is important to remember that hereditary breast cancer is rare.

WHAT ARE GENES?

Genes are a special set of instructions inside the cells of our bodies that parents pass on to their children. Genes contain information, telling our bodies how to grow and work. Genes are also responsible for many things, like the colour of our eyes and the size of our feet.

HOW IS BREAST CANCER LINKED TO GENES?

Our bodies grow with a set of instructions delivered by our genes. Sometimes a gene in a cell develops a fault. As a result that cell may grow abnormally and become cancerous. If you inherit a faulty gene at birth it means that cells throughout the body are much more likely to develop changes leading to cancer.

The instructions of each gene are like a code. Sometimes the code changes and is different to a normal gene. For example, imagine the code for a normal gene is:

1-2-3-4-5-6-7-8-9-10-11-12-13

A cancer gene passed down through a family may have a mistake, giving a slightly different code:

1-2-3-4-5-6-7-8-9-**9**-10-11-12-13

The gene will give a different instruction to the cell it controls. As a result, it can make it grow in a different way. Only when a serious change occurs in the gene does a problem occur. There are a number of genes that can cause breast cancer when they contain such faults. The two most commonly tested for are called BRCA 1 and BRCA 2. Faults in these genes are associated with high risks of developing breast or ovarian cancer.

BRCA stands for BReast Cancer genes 1 and 2.

WHO MIGHT BE AT RISK OF HAVING HEREDITARY BREAST CANCER?

Those with:

- A blood relative who has developed cancer in both breasts.
- Two or more first degree relatives with breast cancer under the age of 50 or ovarian cancer at any age.
- A first degree relative with a known breast cancer gene.
- A male relative with breast cancer.
- An ethnic background where a faulty gene is more commonly inherited, for example, Ashkenazi Jews.

A first degree relative can be your mother or father, sister/ brother or child.

Individuals who inherit a known cancer gene will not definitely develop cancer, but have a high risk of developing cancer compared to the wider population.

WHAT SHOULD I DO IF I HAVE A STRONG FAMILY HISTORY?

If you are concerned about having a strong family history, it is important to discuss these concerns with your GP. You will be asked to give more information on family members that have or have had breast, ovarian and other cancers. Details will be required regarding the age at which the



family member first got cancer and the type of cancer(s) that developed. You may then be referred to a family risk assessment unit.

WHAT HAPPENS AT A FAMILY RISK ASSESSMENT UNIT?

At this unit your family history will be looked at more closely and, where possible, the information regarding cancer cases will be checked and confirmed. Your personal risk of developing breast cancer will be defined, if possible, as low, medium or high risk.

In some situations it is very difficult to say if someone is a carrier of the breast cancer gene. Genetic testing (screening) is not carried out at the family risk assessment unit.

WHAT IS GENETIC TESTING?

Genetic testing involves taking a blood sample. This sample is sent to a specialist laboratory to try and find the particular fault in the gene. Genetic testing takes many weeks to carry out. The search for a fault is like looking for a single spelling mistake in a very large book.

If you do require genetic testing you will be given appropriate information and counseling before the test takes place and after the result is available. Genetic testing is currently only suitable for people with a strong family history.

WHO CAN BE TESTED?

Genetic testing within a family consists of 2 stages.

1. In order to find the fault on the gene, a member of your family who has or has previously had breast cancer has to be tested first.
2. If a fault is found in that family member then genetic testing can be offered to others in the family. It is an individual choice for each family member whether or not they wish to be tested.

Genetic testing is carried out at the National Centre for Medical Genetics at Our Lady's Hospital for Sick Children at Crumlin and St. James Hospital Dublin.

WHAT KINDS OF RISK GROUPS ARE THERE?

- Low risk: This means your breast cancer risk is about the same as the rest of the population. You should continue to be breast aware, and attend the National Breast Screening Programme when invited.
- Medium Risk: This means you have a medium risk compared to the rest of the population. Depending on your age, you may be invited for a mammogram and offered screening at a younger age or more regularly. You will be given support and information that is relevant to your needs.

- High Risk: This means you have a high risk of developing breast cancer compared to the rest of the population. If you are at high risk you need expert advice on how to reduce your risk and what measures you need to consider in terms of screening, surgery, lifestyle and medication.

If you inherit a known breast cancer gene, it does not mean you will definitely develop breast cancer. Whatever your risk group, it is important to continue being breast aware and to report any changes to your doctor. It is also important to update your family history and to let your doctor know if any of your family develop breast, ovarian or other cancers.

WHERE CAN I GET MORE ADVICE?

If you are concerned about a family history of breast cancer talk to your GP. He or she may refer you to a family risk assessment clinic. For further information call the National Breast Cancer Helpline on freefone 1800 30 90 40.



HELP FROM ACTION BREAST CANCER

Action Breast Cancer, a programme of the Irish Cancer Society, provides breast cancer information and support and funds breast cancer research. Our services are free, confidential and accessible.

For more information call the National Breast Cancer Helpline on freefone 1800 30 90 40 or visit www.cancer.ie/action

ORGANISATIONS

Action Breast Cancer
43 / 45 Northumberland Road
Dublin 4
Freefone Helpline: 1800 30 90 40
Email: abc@irishcancer.ie

Irish Cancer Society
43 / 45 Northumberland Road
Dublin 4
Freefone Helpline: 1800 200 700
Email: helpline@irishcancer.ie

Reach to Recovery
43 / 45 Northumberland Road
Dublin 4
Freefone Helpline: 1800 30 90 40

Voluntary Health Insurance
VHI House
Lower Abbey Street
Dublin 1
Callsave: 1800 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

Quinn Healthcare
Mill House
Fermoy
Co. Cork
Locall: 1890 70 08 90
Email: info@quinn-healthcare.com
Website: www.quinn-healthcare.com

Hibernian Healthcare
Hibernian Health
Po Box 764
Freepost
Togher
Co. Cork
Phone: 1850 716 666
e-mail: support@hibernianhealthinsurance.ie
Website: www.hibernian.ie

USEFUL WEBSITES

Irish Cancer Society
www.cancer.ie

Breast Cancer Care UK
www.breastcancercare.org.uk

Cancer Backup
www.cancerbackup.org.uk

American Cancer Society
www.cancer.org

The Susan G. Komen Foundation
www.komen.org

Europa Donna
www.cancereurope.org/europadonna

ABC – ACTION BREAST CANCER

Action Breast Cancer, a programme of the Irish Cancer Society, is the leading provider of breast cancer information and support in Ireland. Each year we reach over 25,000 women who are concerned about breast cancer or breast health. Our services are free and include:

- **National Breast Cancer Helpline** 1800 30 90 40 – staffed by specialist cancer nurses.
- **Patient care programmes** – providing emotional support and practical assistance for those living with breast cancer.
- **Health Promotion** – providing community and workplace programmes on breast awareness and leading a healthy lifestyle.
- **Advocacy** – providing a voice for those affected by breast cancer in Ireland.
- **Professional support** – complementing the services offered by those caring for breast cancer patients.
- **Research** – funding vital Irish research that will have a significant impact on the diagnosis and treatment of breast cancer.

ABC is funded entirely by donations from the public. If you would like to support our work or make a donation please contact us.



a programme of
irish cancer society

Freefone Helpline
1800 30 90 40

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