Cancer and genes

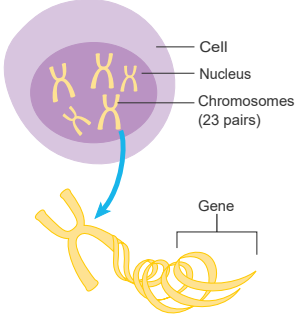
Irish Cancer Society

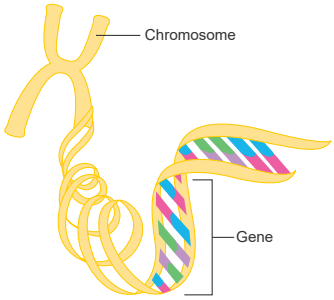
This factsheet is for people who are worried that cancer might run in their family because they themselves or their relatives have had cancer. It may also be helpful for people who want to know more about genetic causes of cancer and genetic testing. For example, if you have been referred for testing or if a genetic change has been identified in you or your family.

If you have any questions or concerns, call our Support Line on Freephone 1800 200 700 or visit www.cancer.ie

What are genes?

Our bodies are made up of tiny building blocks called cells. There are genes in every cell. Genes contain your genetic material (DNA). They contain the information a cell needs to work properly. Genes control the way cells grow, repair and die.





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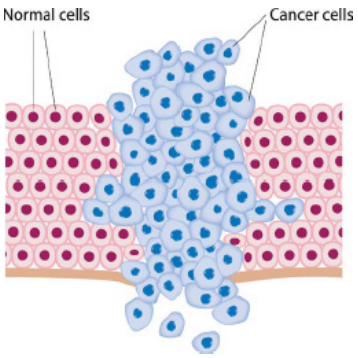
Cancer and genes

Cancer is usually caused by changes in certain genes. For example, genes that control how cells grow and multiply or genes that help repair DNA. These changes mean the gene no longer gives the correct information to the cell. This can cause abnormal cells that start to grow out of control. These cells are cancer cells.



Gene changes that happen during our lifetime (acquired genetic alterations)

Most cancers are caused by genetic changes that happen (are acquired) during a person's lifetime. These genetic changes cannot be passed onto family. Many things can cause acquired genetic changes, including:

- Exposure to things in our environment like tobacco smoke, certain viruses, such as HPV, and UV rays in sunlight
- Our diet
- Our hormones

Things that increase the chance of acquired genetic changes are called **carcinogens.** For example, chemicals in cigarettes and alcohol are carcinogens. It can take years for a gene to change and cause cancer. This is why cancer is more common in older people.

For more information on the things that increase your cancer risk, visit www.cancer.ie/reduce-your-risk or call our Support Line on Freephone 1800 200 700.

Gene changes that are passed on in families (inherited or hereditary genetic alterations)

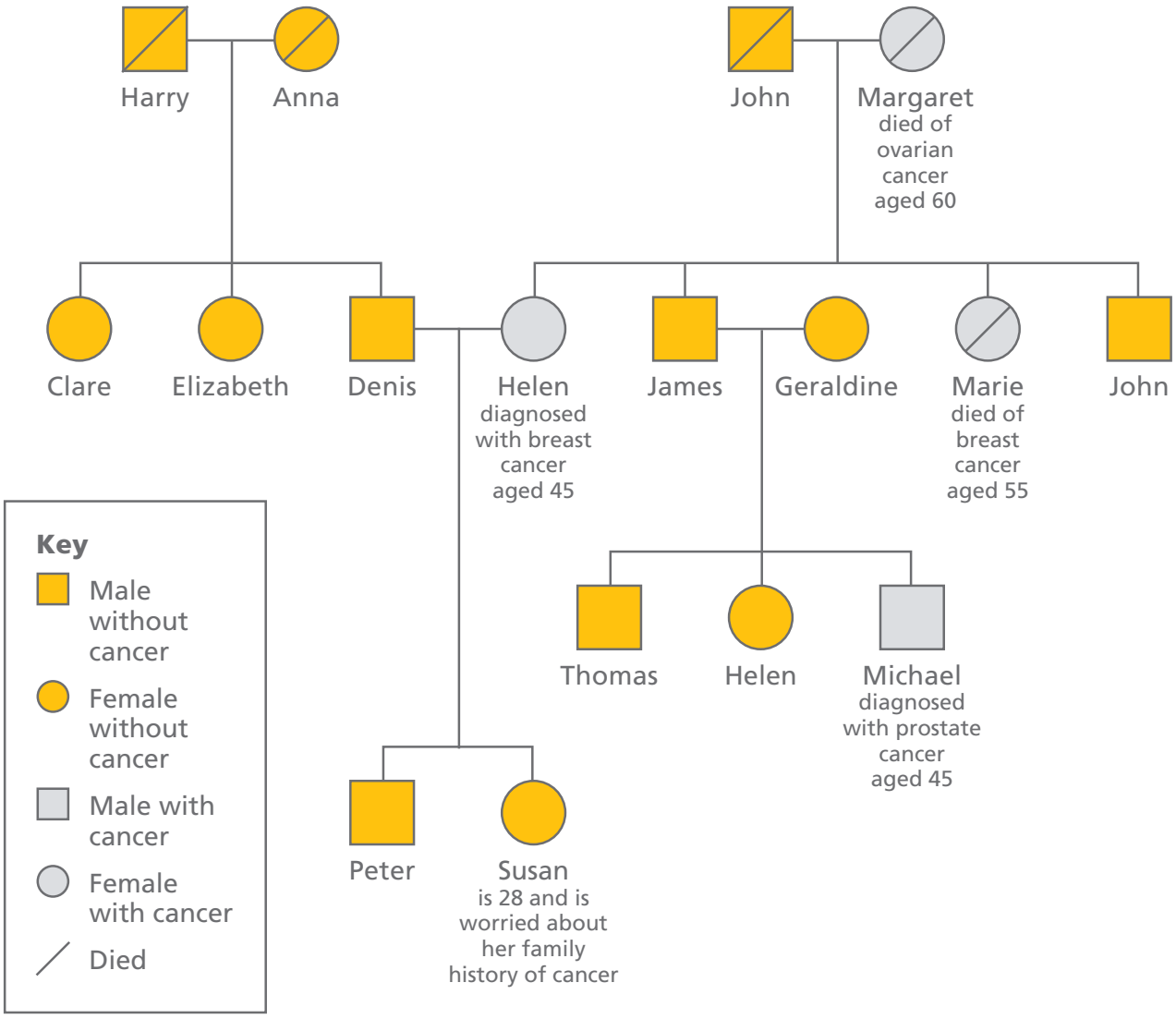
We have 2 copies of most genes. We inherit one copy from our mother and one copy from our father. The child of a parent with a genetic change has a 1 in 2 (50%) chance of inheriting the same genetic change from their parent.

When a person inherits a genetic change that increases their cancer risk, it doesn't mean they will definitely get cancer. Some genetic changes increase the risk of cancer more than others, and some increase the risk of more than one cancer type. An inherited genetic change also increases the chance of developing cancer at a younger age.

Words you might hear:

- **Genetic alteration:** A change in a gene.
- **Pathogenic variant:** A genetic change that can increase the risk of developing a disease.

Family tree showing a pattern of cancer that could be inherited



Most cancers are not caused by an inherited genetic change. Around 5-10% of cancers are clearly linked to an inherited genetic change.

Does cancer run in my family?

Cancer in your family may be caused by an inherited genetic change if:

- You have a close ('first degree') relative, such as a parent, brother, sister or child, who has been diagnosed with 2 separate cancers. For example, bowel cancer and endometrial (womb) cancer
- 2 or more close relatives on the same side of your family have had the same cancer
- You or one of your relatives have a cancer most commonly seen in the opposite sex (for example, male breast cancer)
- You have Ashkenazi Jewish ancestry
- You have had cancer at a younger age than commonly seen (for example, bowel cancer under the age of 50)

This list is a guide only. If any of the above points apply to you, it is possible, but not certain, that you have an inherited genetic cause for cancer in your family.

What to do if you're worried about a history of cancer in your family

If you're worried that cancer might run in your family, your first step is to visit your family doctor (GP). They will ask questions to assess your risk of cancer. This is based on your family history of cancer. If your GP thinks that there may be an inherited cause for cancer in your family, they will refer you to a genetics clinic. If your GP thinks you may be at increased risk of breast cancer, they may refer you to a specialist breast clinic.

If your GP refers you to the clinic, you may have to wait some time – perhaps a number of months – before the cancer genetics team reviews your case.

The genetics clinic

The genetics clinic aims to:

- Identify people who may have inherited a genetic change that increases their cancer risk
- Provide counselling, information and support for people undergoing testing
- Provide counselling, information and advice on managing increased risk when a genetic change is identified

Looking at your family history

To identify if cancer might run in your family, the team at the genetics clinic will look at your family history of cancer. They will use the information from your GP, but they will need a lot more information from you. They will send you a detailed questionnaire to fill out. Some of the questions may include:

- Names and ages of all your family members (both living and dead), usually beginning with your grandparents
- How you are related to them
- Whether they are on your mother's or father's side of the family
- Which cancers your relatives have had
- The age they were diagnosed

Don't worry if you're not able to find out everything. The genetics service will understand.

Based on the information provided to them, the genetics clinic will assess if there is likely a genetic link and if you are likely to benefit from testing and / or counselling support.

Gathering information about your family history of cancer may be difficult. For example, family members may find that talking about cancer brings back painful memories.

Cancer risk assessment

As part of your cancer risk assessment, you will likely be given information on risk categories. This will help the clinic to decide if you might benefit from genetic testing.

A risk category doesn't tell you if you will get cancer – It tells you if the risk is the same or higher than average.

From looking at your family history, the clinic will describe risk as one of the following:

- **Population risk**

  Your family history does not show that you're at increased risk of cancer. You will not need genetic testing or extra screening. But it's important that you take part in national screening programmes(BowelScreen, BreastCheck and CervicalCheck) when invited.

- **Medium (moderate) risk**

  Your family history shows that you may have a slightly increased risk of cancer. You probably won't need genetic testing, but the genetics clinic may recommend extra screening. They will write to you and your doctor with a plan recommending any screening tests or other care you may need.

- **High risk**

  If there is a strong history of certain types of cancer in your family, the clinic may offer genetic testing to you or someone in your family. The testing aims to find out what is causing the increased risk of cancer in the family. This is called diagnostic genetic testing.

  If testing finds a gene change that increases your risk of cancer, the clinic will tell you what the gene change means for your cancer risk. Depending on how high the risk is, screening or risk-reducing surgery may be recommended for you. The clinic may also offer genetic testing to other members of your family, to see if they might have an increased cancer risk. This is called predictive testing. There is more about genetic testing on page 7.

Whatever your risk, it's very important to be aware of the signs and symptoms to look out for. This can help you find cancer earlier if it does happen. For more information see www.cancer.ie

Genetic counselling

If you are referred to the genetics clinic, you will meet with a genetic counsellor. If possible, bring someone with you on the day for support. You can also talk to the counsellor over video call or on the telephone.

What is a genetic counsellor?
The role of the genetic counsellor is to help you to understand your cancer risk and to support you.

Depending on your situation, your genetic counselling may include:

- A detailed look at the medical history of your close blood relatives. The counsellor will draw up a family tree and use this to assess your cancer risk. See page 3 for a sample family tree showing a pattern of cancer that could be inherited.
- A discussion about genetic testing, including how it's done, the risks, benefits and limitations.
- Information on current legislation about genetic testing, insurance and confidentiality.
- Information on cancer screening recommendations and referrals.
- Support and advice for the future if genetic testing identifies an inherited genetic cause for cancer in your family, including a discussion about telling relatives relatives and the best way to do this.
- Information about relevant support groups.
- A written summary of the consultation.

Your emotions

Hints &Tips

Looking into a family history of cancer and deciding whether to go for genetic testing can be very emotional.

It is important to use support from family and friends at this time. Talking through your situation with a loved one can help you make the right decision for you. Having a genetic test is a decision you make yourself. It is not made by medical staff. It can help to write down a list of questions and answers about what a positive result would mean for you and your family.

You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for a confidential chat with a cancer nurse.

Genetic testing

Genetic testing is when the laboratory looks for an inherited cause for cancer in your family. They do this using a sample of your blood or saliva (spit).

If a genetic test shows you have inherited a gene change that increases your cancer risk (a pathogenic variant), it can have a huge impact on your future and that of your family. The genetic counsellor will give you information and support to help you.

Types of genetic testing

Diagnostic testing

Diagnostic testing is carried out to look for a genetic change in families with a strong history of cancer. It is usually done on a family member who has had cancer. The genetics team look closely at one or more genes to try to find the genetic change responsible for the cancer in the family. If a genetic change is found, other members of the family can then choose to have a predictive genetic test. Genetic testing is not usually done until after the age of 18, as most genetic changes are not associated with cancer risk in children or teenagers.

Predictive testing

Predictive testing is for people who have a family member or members with a known genetic change that increases the risk of cancer. With predictive genetic testing, the genetics team already knows which specific gene change to look for and where to find it.

People with a known genetic change in their family may be offered predictive genetic testing to see if they have the same genetic change that has been identified in one or more of their family members.

In Ireland, adult genetic testing is done at St James's Hospital Cancer Genetics Service, at the Department of Clinical Genetics, Children's Health Ireland (CHI), Crumlin and at other centres. For example, CHI has outreach clinics in University Hospital Galway, University Hospital Limerick and Cork University Hospital.

Advantages and disadvantages of genetic testing

If you are offered genetic testing, it is important to be aware of both the advantages and disadvantages before you make a decision.

Possible advantages of genetic testing

- If your test finds you have inherited a genetic change increasing your risk of cancer, you can plan how to reduce your risk. Your genetic counsellor will describe all your options to help you manage your risk of cancer. This might include screening, lifestyle changes or risk-reducing surgery.
- If your test identifies a gene change that increases the risk of cancer in your family, other family members can be tested, to see if they have the same gene change.

Possible disadvantages of genetic testing

- Having the test does not change whether or not you have inherited a genetic change. But knowing may make you feel more anxious. The future may seem uncertain.
- You may not get a clear answer. Your test may show a gene change, but experts may not be sure how this change affects your cancer risk. This may leave you feeling worried and uncertain about the future.
- If your test finds a genetic cause for the cancer in your family, you will be encouraged to notify your close blood relatives. This can sometimes be difficult.

Genetic test results

If a genetic change is found

If a genetic change is found that increases your risk of cancer (a pathogenic variant), this means that your risk of developing cancer is higher than the general population. How much your risk is increased and what you should do about it depends on the particular gene change. Your genetic counsellor can give you more information about this.

Your counsellor or nurse will give you an individual plan for surveillance, such as screening tests or other risk-reducing measures. If you have a genetic change that puts you at high risk of a particular cancer, you may be offered risk-reducing surgery. This means having surgery to remove the part of your body that could be affected by the cancer that is linked to the gene change. For example, if you have a change that puts you at high risk of breast cancer, risk-reducing surgery would involve surgery to remove your breasts (mastectomy).

- **Your feelings:** Finding out that you have a genetic change is likely to be an emotional time. Your genetic counsellor will help you to talk about your feelings. They will also give you careful advice on your options.
- **Telling your family:** Telling your family can be a difficult task. The genetics team will give you a letter to give to your family and advice about what to say. Your family can then decide to have genetic counselling and possibly have genetic testing themselves.
- **Cancer risk and insurance:** If you know you have a gene that increases your risk of cancer because you have had a genetic test, you **do not** need to tell a mortgage provider/insurance company about this.

If no genetic change is found

If you have a **predictive genetic test** and doctors do not find the genetic change they were looking for, it means your cancer risk is likely to be similar to that of someone in the general population. But the results of genetic tests are not always straightforward.

If you have a **diagnostic test** and no genetic change is found, the genetics clinic may still suggest you or your relatives have extra screening based on your family history. This is because there are limitations to genetic testing. Experts may not be able to rule out all inherited causes of cancer. Rarely, the genetics team can find a genetic change but may be unsure if this change is actually the cause of cancer in your family. This is known as a 'variant of unknown significance' (VUS). They will recommend appropriate screening based on your family history. An uncertain result can be difficult to cope with, but the genetics clinic will support and advise you. You can also call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

It's important to remember that we are learning more about cancer genetics all the time. Knowledge and guidelines may change because of new information from research studies.

Cancer awareness

It is important for everyone to be aware of the signs and symptoms of cancer, especially if you are at an increased risk of cancer. A healthy lifestyle can reduce your risk of cancer. This includes not smoking, keeping a healthy weight, staying within low-risk limits for alcohol, and eating a healthy diet.

For more information on spotting cancer early and reducing your risk of cancer, visit www.cancer.ie/reduce-your-risk or call our Support Line on Freephone 1800 200 700.

Inherited (hereditary) cancers

5–10% of cancers are clearly linked to an inherited genetic change. Here, we describe some common genetic changes that increase your risk of cancer.

Hereditary breast cancer and ovarian cancer

Breast cancer is the most common cancer in women in Ireland. Having 1 or even 2 older relatives with this cancer is unlikely to increase your risk.

The genes most commonly associated with a high risk of developing breast or ovarian cancer are called BRCA1 and BRCA2. There are other genes that can increase your risk. BRCA gene changes are also linked to other cancers, such as male breast cancer or prostate cancer. For more information or if you are worried about breast or ovarian cancer, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Hereditary colorectal (bowel) cancer

Over 2,500 Irish people are diagnosed with bowel cancer each year. Having one older relative with bowel cancer is unlikely to increase your risk. Around 5% of bowel cancers are related to inherited genetic changes. There are many known cancer genes related to inherited bowel cancer.

The 2 main conditions linked to inherited bowel cancer are Lynch syndrome / hereditary non-polyposis colorectal cancer (HNPCC) and familial adenomatous polyposis (FAP).

Lynch syndrome (previously and still sometimes known as hereditary non-polyposis colorectal cancer)

Lynch syndrome / HNPCC is the most common gene change that causes bowel cancer. Patients with Lynch syndrome tend to get bowel cancer at a younger age. It also increases the risk of other cancers.

For further information on Lynch syndrome, visit our website **www.cancer.ie** or call our Support Line on 1800 200 700.

Familial adenomatous polyposis (FAP)

Familial adenomatous polyposis (FAP) is a rare genetic condition where hundreds or thousands of polyps develop in the bowel. These polyps or adenomas start to grow during teenage years. If left untreated, they can develop into cancer.

For further information on FAP, visit **www.cancer.ie** or call our Support Line on 1800 200 700.

Genetics resources in Ireland

Clinical Genetics at Children's Health Ireland
Genetics clinic with outreach clinics in University Hospital Galway, University Hospital Limerick and Cork University Hospital
www.childrenshealthireland.ie/list-of-services/clinical-genetics/

Cancer Genetics Service, St James's Hospital
Genetics clinic
www.stjames.ie/services/hopecancergeneticsservice/

It is also possible to pay for private genetic testing. Your GP can advise you about this.

CANCER AND GENES ADVISERS

Eoin Hanney, EBMG Registered Genetic Counsellor
Aoife O'Shaughnessy-Kirwan, Registered Genetic Counsellor

For more information

For more information on cancer and genes and genetic testing, or for confidential advice from our cancer nurses:

- Visit an Irish Cancer Society Daffodil Centre. Centres are located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information. For details of your nearest Daffodil Centre, call 1800 200 700 or visit **www.cancer.ie**

- Call our Support Line Nurses on Freephone 1800 200 700
  Email the nurses: supportline@irishcancer.ie
- Visit our website: **www.cancer.ie**

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