Cancer and genes

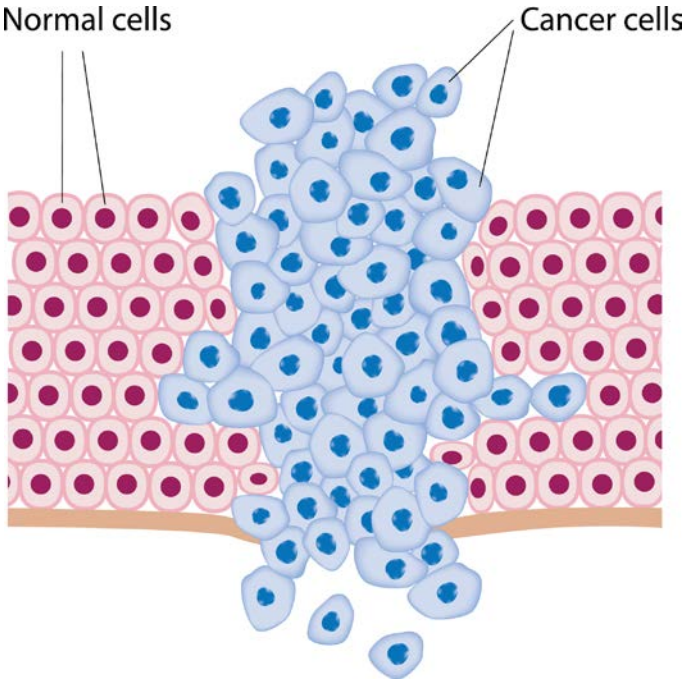
This factsheet is for people who are worried that cancer might run in their family because a number of relatives have had it. It is also for people who are considering genetic testing. If you have any questions or concerns, call our Cancer Nurseline on Freephone 1800 200 700 or visit **www.cancer.ie**

Genes and inherited cancers

What are genes?

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

Cancer happens because something has gone wrong with one or more of the genes in a cell. This can make the cell stop working properly but keep growing out of the body's control. These are cancer cells.



Acquired genetic changes

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:

- Our diet
- Exposure to things in our environment like tobacco smoke and sunlight
- 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 Cancer Nurseline on Freephone 1800 200 700.

Inherited genetic changes

Some genes work to protect against the development of cancer. Changes in these genes can interfere with how they should work. Some people are born with an increased risk of cancer because they have inherited a change in these genes from a parent.

We have two 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 50% (1 in 2) chance of inheriting the same genetic change from their parent.

When a person inherits a genetic change increasing their cancer risk, it doesn't mean they will definitely get cancer. But it does significantly increase their chances of developing the disease. There is also a higher chance of them developing cancer at a younger age.

Assessing your risk of cancer

Most cancers are not caused by an inherited genetic change in families. Only 5–10% of cancers are clearly linked to an inherited genetic change.

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

- You have a close relative who has been diagnosed with two separate cancers. For example, bowel cancer and endometrial (womb) cancer
- Two 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.

See your family doctor (GP)

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

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.

Referral to a genetics clinic

The aim of the genetics clinic is to identify people who may have inherited a genetic change that increases their cancer risk. They do this through a detailed review of your family history of cancer. Following this review, they will tell you if you and your close blood relatives need genetic testing. For more information on genetic testing, see page 4.

After your family doctor refers you to the clinic, you may have to wait some time before the cancer genetics team reviews your case.

What's involved?

When the team at the genetics clinic look at your family history of cancer, they will use the information from your family doctor, but 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. Your genetics consultant will understand.

Your risk

Based on the information in your questionnaire, the genetics clinic will assess your risk of cancer as one of the following:

- **Population risk**
  Your risk is similar to that of people without a family history of cancer. You're more likely not to get cancer than to get it. The genetics clinic will let you know by post if you're in this category. You do not need an appointment at the genetics clinic and you will not need extra screening. But it's important that you take part in national screening programmes (BowelScreen, BreastCheck and CervicalCheck) when invited.

- **Medium (moderate) risk**
  Your risk is higher than average, but you are still more likely not to get cancer than to get it. You will probably not need an appointment at the genetics clinic. The genetics clinic will write to you and your doctor with appropriate cancer screening recommendations.

- **High risk**
  You have a higher risk of getting cancer in your lifetime than the average person. But it doesn't mean you'll definitely get it. You may have an inherited gene change that puts you at a higher risk of cancer. You may benefit from an appointment to see a genetic counsellor or genetic consultant in the genetics clinic. It may be appropriate for you or a relative to have a genetic test.

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 in the high-risk category and referred to the genetics clinic, you will first meet with a genetic counsellor. It is important to bring someone with you on the day for support. The role of the genetic counsellor is to help you understand genetic testing and if it is appropriate for you. There are lots of things to think about before having a genetic test. The genetic counsellor will provide you with accurate information about the risks and benefits of genetic testing and your individual options.

Finding out that you have inherited a gene change that increases your cancer risk can have a huge impact on your future and that of your family. For this reason, genetic counselling is a very important part of your referral to the genetics clinic.

Your genetic counselling sessions will 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 7 for a sample family tree showing a pattern of cancer that could be inherited.
- A discussion about genetic testing, including the risks, benefits and limitations
- Information on current legislation about genetic testing, insurance and confidentiality
- Information on cancer screening recommendations and referrals
- A discussion about informing relatives of a positive result and the best way to do this
- Support and advice for the future if the genetic test identifies an inherited genetic cause for cancer in your family
- Information about relevant patient support groups
- A written summary of the consultation

What is 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.

Types of genetic tests

There are 2 main types of genetic tests:

- **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.
- **Predictive genetic testing** is carried out in a family where there is already a known genetic change. The genetics team therefore knows which specific gene change to look for and where to find it.

Predictive testing is faster than diagnostic testing. This is because the genetics team knows specifically which gene change to look for and where to find it.

Advantages and disadvantages of genetic testing

Before you make a decision to have genetic testing, it is important to be aware of both the advantages and disadvantages.

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. Knowledge is power. 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. They will also refer you to a specialist cancer centre.
- If your test identifies a gene change that increases the risk of cancer in your family, other family members can have predictive testing, 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 also 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 be very difficult.

Your emotions

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

It is important to use the 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.

To help you with your decision, you can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a confidential chat with a cancer nurse.

If a genetic change is found

If a genetic change is found, this means that you are at a higher risk than the general population of developing cancer.

Telling your family can be a difficult task. The genetics team will give you a letter to give to your family. They can then decide to have genetic counselling and possibly have genetic testing themselves. Most genetic changes are not usually associated with cancer risk in children or teenagers. Genetic testing is therefore not usually done until after the age of 18.

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.

If a genetic change is not 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 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 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.

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.

An uncertain result can be difficult to cope with but the genetics clinic will support and advise you. You can also call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Inherited cancers

Only 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.

Breast cancer and ovarian cancer

Breast cancer is the most common cancer in women in Ireland. Having one or even two 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.

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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Bowel cancer

Almost 2,500 Irish people are diagnosed with bowel cancer each year. Having one older relative with bowel cancer is unlikely to increase your risk. Only 5% of bowel cancers are related to inherited genetic changes.

There are many known cancer genes related to inherited bowel cancer. The 2 main types of inherited bowel cancer are Lynch syndrome / hereditary non-polyposis colorectal cancer (HNPCC) and familial adenomatous polyposis (FAP).

Lynch syndrome / hereditary non-polyposis colorectal cancer (HNPCC)
Lynch syndrome / HNPCC is the most common gene change that causes bowel cancer. Lynch syndrome causes non-cancerous polyps that can lead to cancer if they are left untreated. 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 Cancer Nurseline 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 large bowel (colon). These polyps or adenomas start to grow during teenage years. If left untreated, they can develop into cancer.

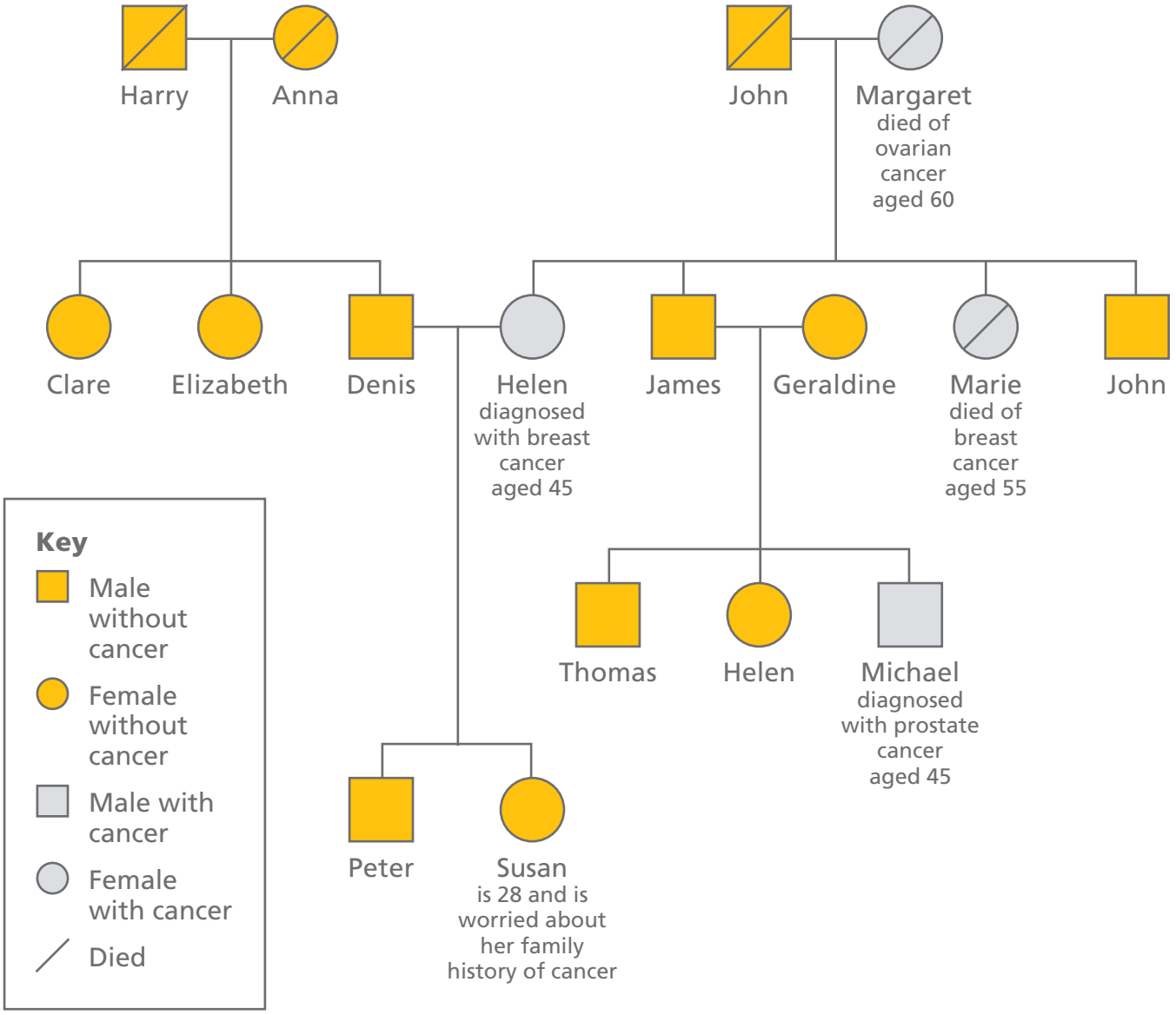
For further information on FAP, visit **www.cancer.ie** or call our Cancer Nurseline on 1800 200 700.

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. You can also make lifestyle changes to reduce your risk of cancer.

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

Family tree showing a pattern of cancer that could be inherited



Genetics resources in Ireland

Our Lady's Children's Hospital, Crumlin
Genetics clinic with outreach clinics in University Hospital Galway, University Hospital Limerick and Cork University Hospital
www.olchc.ie/Services/Departments-A-Z/Department-of-Clinical-Genetics/

St James's Hospital
Genetics clinic
www.stjames.ie/Cancer/ServicesTreatments/CancerGeneticsService

Mater Misericordiae University Hospital
Genetics clinic
www.mater.ie

www.cancergenetics.ie
More information for people with a family history of breast cancer and ovarian cancer

Daffodil Centres

The Irish Cancer Society's Daffodil Centres are located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone affected by cancer. For details of your nearest Daffodil Centre, call our Cancer Nurseline on 1800 200 700 or visit **www.cancer.ie**

For more information on cancer and genes, or for confidential advice from our cancer nurse specialists, call our **Cancer Nurseline** on **Freephone**

1800 200 700

Email: **cancernurseline@irishcancer.ie**
Web: **www.cancer.ie**

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