

# What is Inherited Cancer?

Eoin Hanney

EBMG Registered Genetic Counsellor

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CHI Corporate | Crumlin | Temple Street | Tallaght | Connolly



# Overview

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- Inherited vs Sporadic Cancer
- When to be suspicious?
- What happens if you are referred to Genetics?
- What is Genetic Counselling?

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# “Inherited” vs “Sporadic” Cancer

What is a gene?

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- Genes are like instruction manuals for jobs that the body needs to do
- If there is a spelling mistake or a “paragraph” of the gene missing, it can interfere with how the gene works
- We have genes that are important for controlling cell growth and protecting us from developing cancer
- If someone inherits a spelling mistake (mutation) in one of these genes it can increase their risk of developing certain types of cancer
- This is called inherited or hereditary cancer predisposition
- Most cancers are sporadic, not caused by faulty genes

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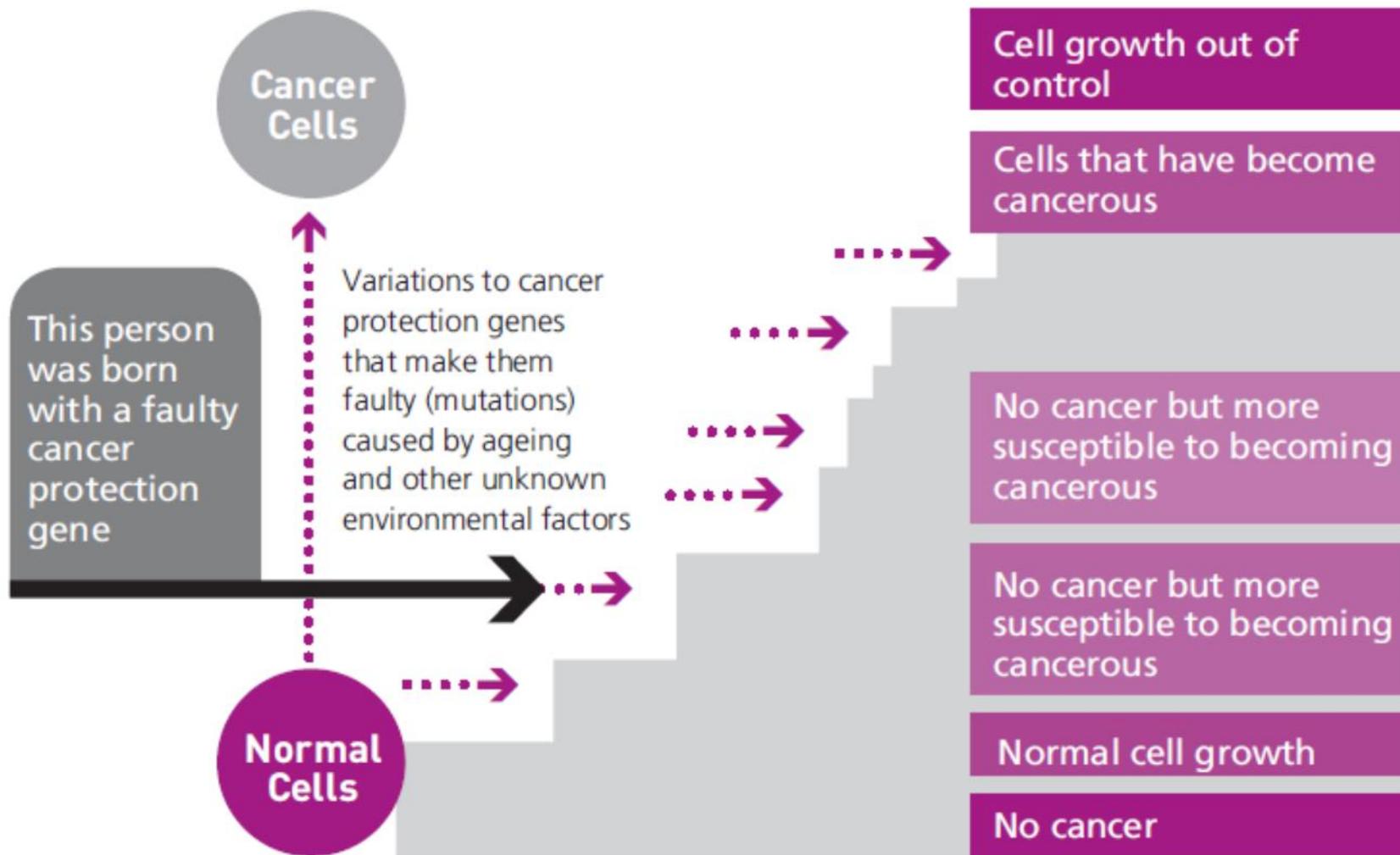


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# “Inherited” vs “Sporadic” Cancer



# “Inherited” vs “Sporadic” Cancer

Which types of cancer are more likely to be inherited?

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- ▶ Approximately 15-20% of ovarian cancers are caused by hereditary/genetic factors
- ▶ 5-10% of breast cancers are caused by hereditary/genetic factors
- ▶ ~5% of colorectal cancers are caused by hereditary/genetic factors
- ▶ Vast majority of cancers not caused by mutations in cancer predisposition genes
- ▶ It is not always possible to identify the cause of a genetic predisposition to cancer in a family

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# Types of Cancer Predisposition Syndromes

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- ▶ Hereditary Breast and Ovarian Cancer syndrome
  - Caused by mutations in the BRCA1 and BRCA2 genes
  - Causes an increased risk of breast, ovarian and prostate cancer
  
- ▶ Lynch syndrome
  - Caused by mutations in MLH1, MSH2, MSH6 and PMS2 genes
  - Causes an increased risk of colorectal, endometrial, ovarian and other types of cancer
  
- ▶ Rarer cancer predisposition syndromes
  - Li Fraumeni syndrome
  - Birt Hogg Dube
  - Hereditary Pheochromocytoma and Paraganglioma syndrome
  - Multiple Endocrine Neoplasia

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# When to be suspicious of hereditary cancer?

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- ▶ Multiple cases of the same type of cancer in a family
- ▶ Multiple cases of linked cancers in a family (breast/ovarian/prostate- BRCA1 & BRCA2)
- ▶ Young age of onset
- ▶ Individuals with more than one different type of cancer
- ▶ Unusual cancer type or tumour subtype

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# What to do if you have a family history of cancer?

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- ▶ Discuss your family history of cancer with your GP, Oncologist or cancer care team
- ▶ If there is a suspicion of inherited cancer, they will refer you to Clinical Genetics
- ▶ You will be sent a family history questionnaire (Please give as much info as possible)
- ▶ Your family history will be reviewed and assessed
- ▶ You may be offered an appointment with a Genetic Counsellor to discuss your family history and genetic testing
- ▶ Alternatively, you may be given reassurance or screening advice but no appointment
- ▶ If you have not had cancer, we may suggest testing of an affected family member
- ▶ It is not always possible to identify what is causing hereditary cancer predisposition within a family

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# What happens if a faulty gene is identified?

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- ▶ You will be given information about the associated cancer risks
- ▶ You may be referred for cancer screening and/or to discuss risks reducing surgical options
- ▶ We can then offer to test other members of the family who are at risk
  - Siblings
  - Children
  - Parents
  - Wider family
- ▶ You will usually get a copy of your result, a summary letter and a letter to pass to relatives
- ▶ In most cases, we do not test children for inherited cancer predisposition syndromes as in most cases the increased risk of cancer only occurs in adulthood

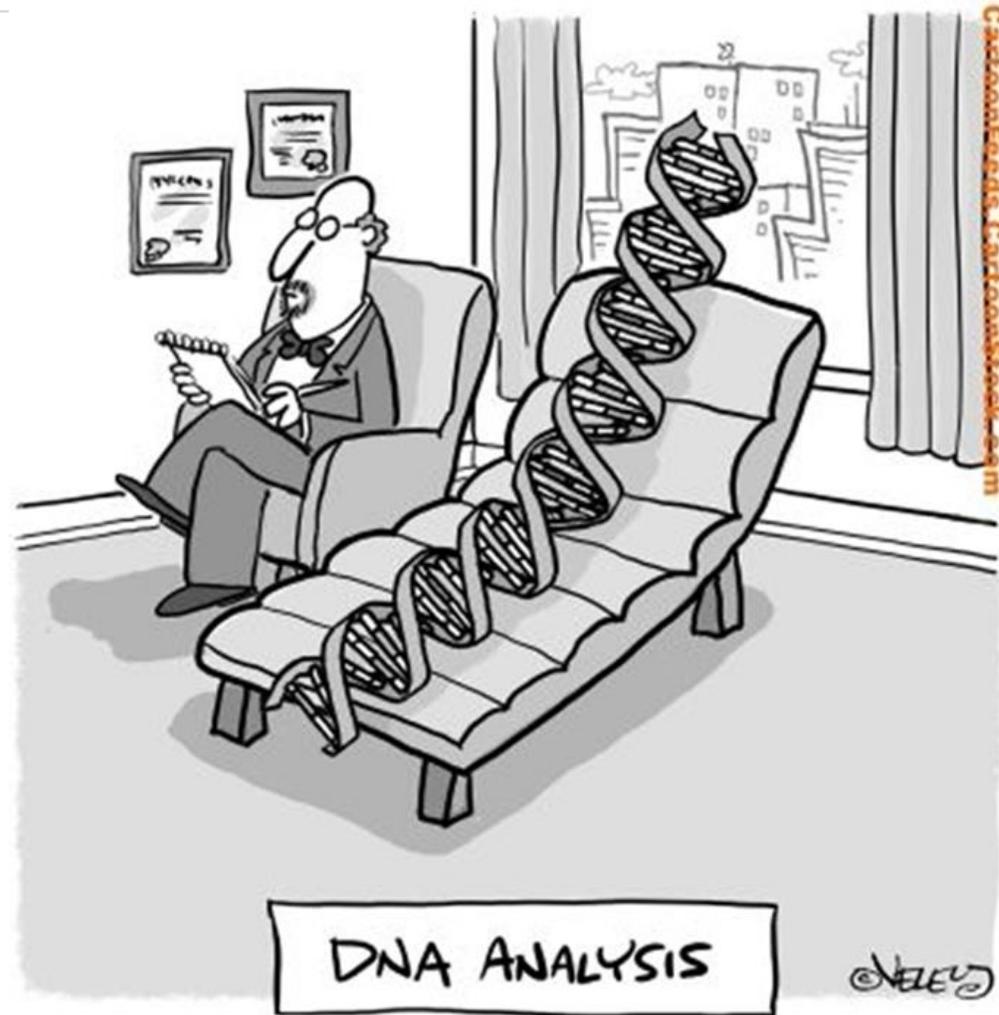
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# What is Genetic Counselling?



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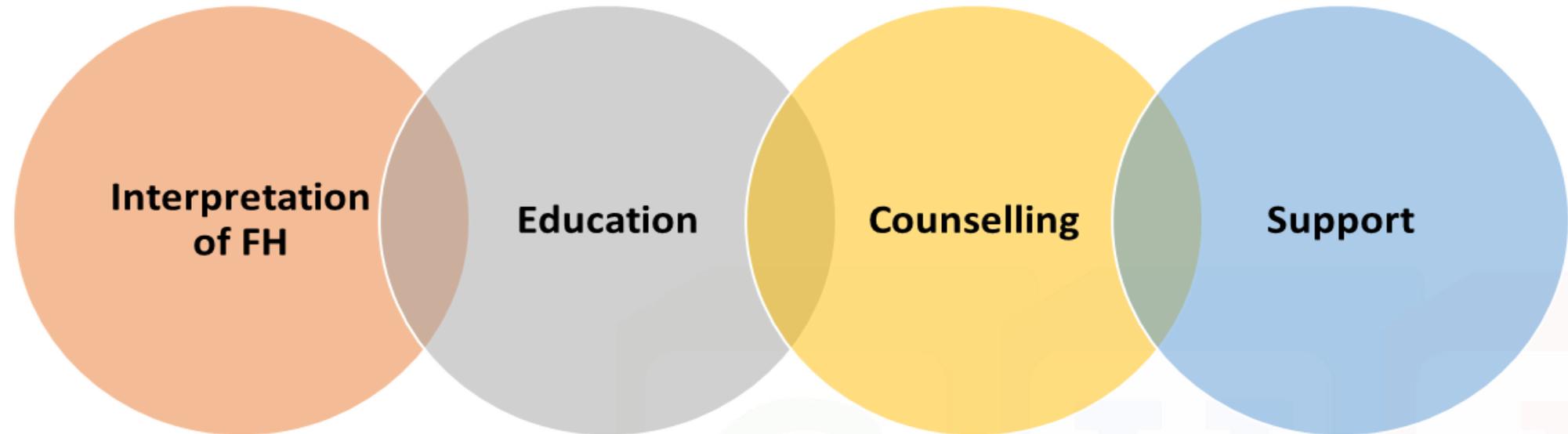


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# Genetic Counselling Definition

“Genetic counselling is a communication process, which aims to help individuals, couples and families understand and adapt to the medical, psychological, familial and reproductive implications of the genetic contribution to specific health conditions.”



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Resta et al, (2006) “A new definition of genetic counselling: NSGC task force report.” J Gen Couns

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# Genetic Counselling Overview

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- Not therapeutic counsellors but MSc level training in molecular and clinical genetics
- Expertise working with families with hereditary cancer syndromes and the impact that a genetic testing can have on a patient and their family
- Formal training in counselling skills and interventions- help individuals discuss their lived experience of cancer
- Encourage patients to prepare for the possible outcomes of testing
- Onward referral for screening/surgery
- Signpost to other support services
- Experts in our field- up to date with latest guidelines/research

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# Genetic Testing

## Benefits and Drawbacks

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- Can identify those at risk of developing further cancer
  - Control/manage risks
  - Can sometimes direct surgical/treatment options
  - Explanation for why cancer had occurred
  - Psychological/emotional impact
- Can allow predictive testing of other relatives
  - Identify those at risk- appropriate screening/risk reducing surgery
  - Increased anxiety/worry and guilt

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# Insurance Implications of Genetic Testing

## The Disabilities Act 2005

42.—(1) Genetic testing shall not be carried out on a person unless—

Genetic testing and processing of genetic data.

(a) the testing is not prohibited by law, and

(b) the consent of the person to the processing of any genetic data to be derived from the testing has been obtained in accordance with the Acts.

(2) A person shall not engage in the processing of genetic data in relation to—

(a) the employment of a person save in accordance with the provisions of section 12A of the Data Protection Act 1988 (as inserted by the Data Protection (Amendment) Act 2003),

(b) a policy of insurance or life assurance,

(c) a policy of health insurance or health-related insurance,

Pr.4 S.42 [No. 14.] Disability Act 2005. [2005.]

(d) an occupational pension, a retirement annuity contract or any other pension arrangement,

(e) the mortgaging of property.

▶ Worries about insurance implications are a major factor in Irish people not coming forward for cancer genetic testing (for themselves and/or children)

▶ Reflected in Irish Cancer Societies recent report

▶ You cannot be asked about the results of a genetic test by any insurer- Life insurance, Health insurance, Mortgage protection etc

▶ Can be asked about personal/family history

▶ WWW. <https://www.insuranceireland.eu/>

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THE UNMET NEED IN CANCER GENETIC SERVICES:  
**CONDUCTING AN ENVIRONMENTAL SCAN  
OF THE CANCER GENETICS SERVICES IN AN  
IRISH CONTEXT UNDERPINNED BY A MIXED  
METHODS APPROACH**

Report prepared for the Irish Cancer Society<sup>1</sup>

April 2021

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- ▶ Cancer genetic services underfunded and under-resourced
- ▶ Mainstreaming/Streamlining diagnostic testing
- ▶ Dedicated pathways post result  
Surgery, screening, support  
Onus currently on patients
- ▶ Action plan
- ▶ Need investment and to look at new models of delivering care

# Thank you Questions?

eoin.hanney@olchc.ie

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