

## Informative guide for patients and their family - From the past to the future of health A history of hereditary or family cancer is not a death sentence

**Project title**: Promoters of advanced oncogenetics open online training and multimedia raise awareness on multidisciplinary assessment of patients and their families at risk of hereditary or familial cancer **Project Acronym:** HOPE - How Oncogenetics Predicts & Educates **Ref. no.** 2018-1-RO01-KA202-049189 **Programme**: Erasmus+

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# What does oncogenetics mean?

Oncogenetic is a medical discipline, which aims to:

- understand genetic predisposition to cancers
- care for persons at risk.

A high frequency of affliction/oncological illness or diagnoses at a young age in a single family may indicate a hereditary susceptibility. Such predispositions are estimated to play a significant impact in around 5% of adult cancers and some paediatric tumours.

Genetic testing can reveal the underlying issue and whether or not family members are susceptible to develop cancer. As a result, suitable preventative and monitoring actions can be implemented.







## What are the factors that enhance the cancer risk?

#### **Family History**

Certain oncological illnesess are substantially more common in some families. Sometimes the elevated risk is caused by a single gene, and other times it is caused by multiple interacting with another. genes one Environmental variables, which are prevalent in the family, may change this genetic connection and lead to cancer.

#### Diet

- A high-fat diet, for example, as well as obesity, have been associated to an increased risk of colon, breast, and perhaps prostate cancer.
- People who consume a lot of **alcohol** are at a significantly • increased risk of developing head and neck cancer as well as esophageal cancer. A diet heavy in **smoked and pickled** foods, as well as grilled meats, raises the risk of stomach cancer.
- **Overweight or obese** people are more likely to develop cancers of the breast, uterine lining (endometrium), colon, kidneys, and oesophagus.

#### **Environmental factors**

- Tobacco smoke contains carcinogens that substantially increase the risk of developing cancers of the lungs, mouth, throat, esophagus, kidneys, and bladder.
- Pollutants in the air or water, such as asbestos, industrial waste, or cigarette smoke, can increase the cancer risk.

#### Infections

Numerous viruses are known to cause cancer in humans, and several more are suspected. Human papillomavirus (HPV, which causes genital warts) is a leading cause of cervical cancer in women, as well as penile and anal cancer in males.



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## Who should come to the oncogenetic consultation?

### > Those who have a family history of:

- breast cancer
- ovarian cancer
- the most common types of hereditary cancer
- prostate cancer 🤳



If a family member has a genetic mutation diagnosis. If a family member has previously undergone genetic testing and it has been verified that he or she possesses a mutated gene that increases the risk of cancer, you are recommended to schedule a "pre-symptomatic" consultation with the Oncogenetic Clinic.

### $\succ$ If you want to simply know the risk of developing a hereditary cancer

<u>IMPORTANT!</u> Experts warn that "50% of women suffering from breast cancer due to genetic causes will be inherited paternal disease" (Gareth Evans, professor of genetics at the University of Manchester, 2016). So, in determining the risk factors, the geneticist will take into account the entire family history, not just the one from the mother.





## How to monitor and evaluate cancer risk based on oncogenetics?

Personal history	Family history
Early onset of cancer diagnosis (e.g. breast cancer < 45 years, colorectal cancer < 50 years)	Three close relatives (same side) with cancer of the same or syndromically related type (breast/ovary, colorectal/endometrium)
Multiple associated primary cancers: breast/ovary, colorectal/endometrium	Two close relatives (same side) with cancer of the same or related type with at least one affected under 50 years
Male breast cancer	One first-degree relative with early onset cancer (breast < 45 years, colorectal < 50 years)
Ovarian, fallopian tube, primary peritoneal cancer	One first-degree relative with multiple primary cancers
Breast cancer and thyroid, sarcoma, adrenocortical carcinoma	Two or more relatives with uncommon cancers (sarcoma, glioma, hemangioblastoma, etc.)
Multiple colon polyps (>10 cumulative)	Relatives of patients with known BRCA, APC, MUTYH, mismatch repair mutations
Colorectal or endometrial cancer with microsatellite instability and/or lack of expression of mismatch repair protein(s) by immunohistochemistry	Many relatives with cancer but no criteria for testing are fulfilled

While there are advantages to genetic testing, it is important to keep in mind that there are also drawbacks.

A positive result from cancer genetic testing does not guarantee that you will develop cancer, but it can have a significant impact on your mind or the minds of your loved ones.

A negative result, on the other hand, does not ensure that you will not get cancer.



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## Why the genetic tests are made?

Genetic testing is ordered to check for signs of a suspected genetic disease that may increase your chance of getting cancers such as breast cancer, ovarian cancer, colon cancer, prostate cancer, and others.

## How the genetic tests are made?

- 1. A physician, advanced practise provider, or genetic counsellor orders genetic testing.
- 2. A blood or saliva sample is taken and submitted to a laboratory for testing once the patient has completed a permission form for genetic testing.
- 3. Technicians will search your DNA for particular alterations linked to an inherited cancer condition.
- 4. The results are generally available in 2 to 3 weeks and are discussed with the genetic counsellor at a post-test follow-up session.
- 5. The results are then sent to your doctor.







## Some advantages of genetic testing include:

- A sense of relief from uncertainty
- Reduce the risk of cancer by making certain lifestyle changes if you have a positive result
- In-depth knowledge about your cancer risk
- Information to help make informed medical and lifestyle decisions
- Opportunity to help educate other family members about potential risk
- Earlier detection, which increases the chance of a successful outcome

## Some disadvantages, or risks, that come from genetic testing can include:

- Testing may increase anxiety and stress for some individuals
- Testing does not eliminate a person's risk for cancer
- Results in some cases may return inconclusive or uncertain



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## **Cancer risk asessment tools**

Before performing a genetic test with an oncologist, there are online tools for assessing the risk of developing a hereditary cancer. The percentage is calculated based on criteria such as age, the existence of cancers in the family and other environmental factors.

There are several tools for assessing the risk of developing different hereditary cancer, made by different entities working in the field, or by projects that reaserch these types of hereditary cancers:

- HOPE Project How Oncogenetics Predicts and Educate Prostate, breast, ovarian cancer
- MI Genetics Resource Center <u>Hereditary breast and ovarian cancer syndrome (HBOC)</u>, and <u>Lynch</u> <u>syndrome (LS)</u>
- Ovarian Cancer Action <u>Breast and ovarian cancer, Lynch syndrome (hereditary non-polyposis colorectal cancer)</u>





## How do we cope with cancer diagnosis?



You may have recently discovered that you have cancer. You might also be in treatment, have recently completed treatment, or have a friend or family member who has cancer. Cancer alters your life as well as the lives of people around you. The disease's symptoms and side effects, as well as its treatment, can cause bodily changes, but they can also impact how you feel and how you live.

## **Feelings and Cancer**

The ideals you were raised with can often influence how you think about and manage with cancer. For instance, some people: They believe they must be powerful in order to protect their friends and family. Seek help from loved ones or other cancer survivors. Seek the assistance of counsellors or other specialists. Turn to their faith for support. Whatever you choose, it is critical that you do what is best for you and not compare yourself to others. Some of your friends and family members may be experiencing similar emotions. Share this information with them if you feel safe doing so.





## **Emotional Coping Techniques (1)**

- Express Your Emotions People have discovered that when they express powerful emotions such as rage or grief, they are better able to let them go. Some people work through their emotions by speaking with friends or family, other cancer survivors, a support group, or a counsellor. Even if you don't want to talk about your disease with others, you may still work through your emotions by thinking about them or writing them down.
- Look for the Good Sometimes this involves searching for the positive even when things are terrible, or striving to be optimistic rather than pessimistic. Concentrate your emphasis on wellness and what you can do right now to keep as healthy as possible.
- Don't blame yourself for your cancer Some people feel they developed cancer as a result of something they did or did not do. However, experts are baffled as to why one individual develops cancer and another does not. Every body is unique. Remember that cancer may strike anybody at any time.







# **Emotional Coping Techniques (2)**

- You Get to Decide When to Talk About Your Cancer It might be difficult for others to know how to approach you about your disease. Often, loved ones have good intentions but don't know what to say or how to act. You can put them at ease by asking what they think or how they feel.
- Be as active as you possibly can Getting out of the home and doing something can help you focus on things other than cancer and the concerns that come with it. Exercise, as well as mild yoga and stretching, might be beneficial.
- Look for Activities You Enjoy You could enjoy carpentry, photography, reading, or crafts. Alternatively, seek out creative avenues such as art, film, music, or dancing.
- **Consider What You Have Control Over** Some people claim that organising their life helps. Among the things you can control are your involvement in your health care, keeping your appointments, and adopting lifestyle adjustments. Even creating a daily plan might help you feel more in control. While no one can control their thoughts, some claim they try not to linger on the negative ones and instead focus on the pleasant aspects of life.





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## **Oncologic patient rights (1)**

#### **1**. The right to early detection, diagnosis and treatment

All cancer patients, regardless of age, gender, or various conditions have the right to early detection of the disease, to the best methods of diagnosis and treatment available.

### 2. Quality of care

The quality of care must be the result of a complex approach, to meet the particular needs of patients and their families, to promote the improvement of the quality of life and to lead to a more efficient use of resources.

#### 3. Patient relationship - health professionals

This relationship must develop in terms of mutual respect and trust and be based on well-defined rights and responsibilities.

#### 4. The informed patient

Access to information for patients and their families must be promoted for a better understanding of the disease and treatments, in order to reduce anxiety and to go through this stage of life in the least stressful way possible.









# **Oncologic patient rights (2)**

#### **5.** Psychological support for patients and their relatives Psychological support is essential for the emotional needs of patients and their families at all stages of the disease, during and after treatment.



#### 6. Social and financial support

The following measures are needed to support the patient and his family:

- Counselling for obtaining social assistance.
- Help in filling in various legal forms.
- Social support both during and after the completion of treatments.
- Other practical, specific measures.

### 7. Rehabilitation

Restoring physical and mental health and increasing the quality of life requires a complex, multidisciplinary approach (physical, social, occupational, psychological and spiritual).

#### 8. Palliation

The right of patients to medical care, which aims to improve the quality of life in the advanced stages of malignancy.

### 9. Social counseling of patients

Concept established in everyday language as "advocacy" (term taken from English), which designates all the actions undertaken individually or through organizations, whose main purpose is the increasingly active involvement of patients in medical decisions, but also in the promotion of health programs and policies.





# Take action, do something for yourself!

