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Genetic Testing for Cancer Risk [1]

This section has been reviewed and approved by the Cancer.Net Editorial Board [2], 01/2015

Key Messages:

- Genetic testing helps predict the likelihood that a person will develop a disease, including some types of cancer.
- Genetic testing is a personal decision with many factors to consider.
- Anyone who chooses genetic testing should get genetic counseling before and after the test.

Genetic testing for cancer risk can help estimate your chance of developing cancer in your lifetime. More than 2,000 genetic tests are available for many different diseases, including breast, ovarian, colon, thyroid, and other cancers. The tests analyze your genes, chromosomes, or proteins to help:

- Predict your risk of a particular disease.
- Find out if you have genes linked with increased cancer risk that can be passed on to your children.
- Determine how to manage increased cancer risk, such as more frequent screening or ways to lower risk.

No genetic test can report with 100% certainty that you will develop cancer. However, the tests can tell you if you have a higher risk of developing cancer than the general population. Not everyone with a gene mutation that increases the risk of cancer will develop the disease. For example, a woman with a 75% chance of developing breast cancer may remain healthy. On the other hand, a woman with a 25% chance of developing breast cancer may eventually develop cancer.

Risk factors for hereditary cancer

The following factors suggest that a person may be at risk for developing a hereditary cancer. A hereditary cancer is any cancer caused by a gene mutation, or change.

- **Family history of cancer.** Three or more relatives on the same side of the family with the same or related forms of cancer

- **Cancer at an early age.** Two or more relatives diagnosed with cancer at an early age
- **Multiple cancers.** Two or more types of cancer occurring in the same relative

ASCO recommends that you consider genetic testing for the following situations:

- You have a personal or family history that suggests a genetic cause of cancer
- The test for the genetic condition can clearly show that you have a specific genetic change
- The results will help with the diagnosis or management of the genetic condition or the cancer(s) it is linked to.

In addition, ASCO recommends genetic counseling both before and after the genetic test. Learn more about ASCO's latest recommendations on genetic testing for cancer susceptibility [3].

Reasons to consider genetic testing for cancer

Genetic testing can help you understand the risk of developing cancer or passing it on to your children. It is a personal decision you should make in collaboration with your family, doctor, and genetic counselor. You may consider genetic testing for the following reasons:

- Help make medical decisions, such as lowering your risk through surgery, medication [4], or lifestyle changes. You may also receive cancer screening [5] tests more often.
- Relieve anxiety, especially if you know your family has a history of cancer from a specific gene mutation
- Ease uncertainty about whether you have a specific gene mutation linked to cancer
- Provide information to your family about you and your children?s chance of having a specific gene mutation

Additional factors to consider

Genetic testing has limitations and emotional implications.

Testing may cause depression, anxiety, or guilt. A positive test result, meaning a gene mutation exists, may make some people anxious or depressed about developing cancer. Some people may start to think of themselves as sick, even if they never develop cancer. If a person does not have the mutation when other members of the family do, this individual may experience guilt.

Testing may cause family tension. A person may feel responsible for telling family members about a positive test result and encouraging genetic testing. This process may lead to tension in the family. Learn more about sharing genetic test results with your family [6].

Testing may provide a false sense of security. Even in a family with a known cancer gene mutation, a person with a negative result may still develop cancer. The negative result only means the person?s risk of developing cancer is similar to the risk for the general population. Additionally, each person?s risk is affected by lifestyle, environmental factors, and personal cancer history.

Testing may provide unclear results. A person's gene may have a mutation that is not currently linked with cancer risk. This is called a variant of unknown significance, meaning it is unclear whether the mutation will increase cancer risk. Or, a person may have a gene mutation that is undetectable with the available tests. Many cancers are not yet tied to a specific gene. Plus, some genes may interact in unpredictable ways with other genes or environmental factors to cause cancer. In either situation, it may be impossible to calculate the cancer risk of the mutation.

Testing can be costly. Genetic testing can be expensive, especially if your insurance doesn?t pay for it.

Testing may cause confidentiality concerns. Some people fear genetic discrimination from test results or feel concerned about the privacy of their genetic information. They may worry about sharing test results with relatives and experiencing employment, health, and life insurance discrimination. Consider discussing privacy concerns with a genetic counselor or doctor.

Genetic discrimination legislation

In 2008, Congress passed the Genetic Information Nondiscrimination Act (GINA). The legislation protects all Americans against discrimination based on their genetic information in receiving health coverage or employment. Learn more about GINA and genetic discrimination. [7]

Questions to ask yourself about genetic testing

Before you have genetic testing, learn about the risks and limitations of testing. It is also important to fully understand your reasons for wanting a test. You should also consider how you will cope with the results of the test. Some questions to help you with your decision making are:

- Do I have a family history of cancer, or have I developed cancer at an earlier-than-average age?
- How will I interpret the results of genetic testing? Who will assist me in using this information?
- Will knowing the test results affect my medical care or the medical care of my family?
- If I have a genetic condition, are there steps I can take to lower my risk?

A genetic counselor can help address these questions. Genetic counselors are professionals specially trained to advise people about the risks and benefits of genetic testing. They can also help people through the process of testing and interpreting the results. Learn more about what you can expect when meeting with a genetic counselor [8].

More Information

Understanding Cancer Risk [9]

The Genetics of Cancer [10]

Understanding Statistics Used to Estimate Risk and Recommend Screening [11]

Additional Resource

National Human Genome Research Institute: Issues in Genetics [12]

Links:
[1] http://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/genetic-testing-cancer-risk
[2] http://www.cancer.net/about-us
[3] http://www.asco.org/press-center/asco-helps-doctors-and-patients-sort-through-genetic-testing-issues
[4] http://www.cancer.net/node/24973
[5] http://www.cancer.net/node/24972
[6] http://www.cancer.net/node/24906
[7] http://www.genome.gov/10002328
[8] http://www.cancer.net/node/24907
[9] http://www.cancer.net/node/25007
[10] http://www.cancer.net/node/24897
[11] http://www.cancer.net/node/24960
[12] http://www.genome.gov/Issues/