

Genetic Testing for Cancer: Is It Right for You?



Cancer Risk and Prevention Program

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CANCER CARE NETWORK
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For More Information

How to use this guide

This guide has many sections for you to write down questions. You will find these located at the bottom of most pages. We will help you answer these questions.

Still have questions?

For more information go to: mainehealth.org/cancer. This website offers information on genetic testing, diagnosis, treatment, prevention, survivorship and much more.

You can also call the MaineHealth Cancer Care Network and Referral Line toll-free at 1-844-944-8094

Notes:

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After Genetic Testing

Sometimes this testing process can cause a lot of stress and difficult feelings. We have experienced staff available to help with any questions or concerns you may have. Please call our staff if you are experiencing difficult feelings about the genetic testing process and need help.

We want to hear how you and your family are doing!

After genetic testing:

- We ask that you keep in touch with us at least once a year so that we can update you on any new information on genetic risk for cancer.
- We also ask that you let us know about any new medical information for you or your family that may affect your cancer risk. This could include a diagnosis of a new cancer, a positive genetic test result, or pre-cancerous findings in yourself or other family members.

Questions?

The Cancer Risk and Prevention Program staff members will answer any questions or concerns that you may have about your genetic testing. The staff can be reached at 207-396-7788.

- Cancer genetic testing is one part of the puzzle in understanding your risk for cancer.
- Cancer genetic testing might guide you in your ongoing medical care.
- There are many steps you can take to lower your risk of cancer. We can help you with that.

Genetic Testing for Cancer: Is it Right for Me?

Genetic testing usually involves a simple blood test sent to a lab where they look for changes in cancer-related genes.

Genetic testing is a very personal choice.

As part of your cancer genetic counseling, we will help you to consider many of the issues and concerns of cancer genetic testing.

Sometimes people with cancer or a family history of cancer can be tested. Not everyone with cancer or a family history of cancer will have a gene change that can be found with testing. **In fact, most people will not have such a change.**

We can help you decide if genetic testing is right for you. If you have any questions, the Cancer Risk and Prevention Program team will do their best to answer them.

We want you to make the best choice possible for you and your family.



What Will Genetic Testing Mean for Me?

What will my genetic test results mean?

Personal and family medical history plays a large part in understanding your genetic test results. The advice of your doctor is also important in understanding what your genetic test results mean for your future health.

Genetic test results are: positive, negative, or uncertain.

- **Positive:** A mutation (change) was found. This result means that you have a **higher risk** for cancer.
- **Negative:** No mutation (change) was found. This result means that you **may still have a higher risk** for cancer based on your personal and family medical history.
- **Uncertain:** A genetic change was found but it is not clear whether the change is related to an increased risk for cancer. This result means that you **may still have a higher risk** for cancer based on your personal and family medical history.

Questions?

Other Questions?

Can I choose not to be tested?

You can choose not to have genetic testing at any time before your blood sample is taken.

What do I need to do before the test?

- Provide the information requested on the cancer types in your family.
- If a family member has already been tested, then we will need to see a written copy of the test results.

How will I receive my genetic test results?

- Cancer Risk and Prevention Program staff will give you your test results.
- When returning for your results, we suggest bringing a friend, your spouse or your partner instead of a relative. Relatives may learn that they are also at a higher genetic risk for cancer. This may be upsetting to them.

What will happen to my genetic test results?

- Your genetic test results will be put in your medical record at MaineHealth.
- You will be given a copy of your test results.
- At your request, we will send a copy of your results to your doctor(s) or other clinicians.
- We strongly advise that you share your genetic test results with others in your family.

Are my tests confidential?

Yes. Your tests are confidential. We will not share your information with anyone, unless you ask us to do this for you.

Insurance and Costs

How will this affect my insurance?

- You might worry that your genetic test results could be used against you by your insurance company. There is very little proof of this.
- Laws have recently passed that will help to protect you against health insurance discrimination.
- Your ability to get life insurance and disability insurance may be affected by genetic testing.

What are the costs of genetic testing?

- Your insurance company may pay for all or some of the costs of genetic testing.
- Some genetic tests may need to be pre-approved by your insurance plan before you have any testing done.
- Even if your insurance plan approves the test, it does not always mean that the test will be paid for completely. You must speak to your insurance company about this.
- You must be able to pay for whatever costs your insurance does not cover.

What questions do you have about your insurance coverage and the costs of genetic testing?

Genetic Testing: One Piece of the Puzzle

- Positive genetic test results predict risk for cancer. You may or may not get cancer. You may or may not develop a second cancer if you already had cancer.
- Genetic test results usually cannot tell you which treatments you should take if you get cancer.
- If someone in your family has a positive genetic test result (a mutation) and you do not, it is still important for you to get cancer screenings, and make choices that are good for your health.
- If no one in your family has a positive genetic test result (a mutation), then a negative result gives little information. Your cancer risk may still be increased.
- Not all cancers can be found early or prevented.
- Genetic tests are as accurate as possible. However, as with any test, results may not be 100% accurate.

Questions?



Benefits of Genetic Testing

What are the benefits of genetic testing for me?

- Genetic test results may make you feel better and less worried.
- Genetic test results may give you more information about your cancer risks and help your doctor plan for your care.
- If you have a positive genetic test result (a mutation), you are more likely to get cancer and can choose which steps to take to find cancers early or to lower your risks of cancer. This may include planning future screening tests or preventive treatments.
- If someone in your family has a mutation and you do not, you can avoid certain screening tests or preventive treatments as long as you don't have other risk factors for cancer. You will likely have the same cancer risks as everyone else. You will still need to have routine check ups by your doctor, and should have regular cancer screening tests.

What are the benefits of genetic testing for others?

- Test results may help you understand your family's cancer history.
- These results may give more information to your family about their cancer risks and can help their doctors plan for their care.
- You may learn about the chances your children, or relatives have of a mutation (positive genetic test result).

Risks of Genetic Testing

What are the risks of genetic testing for me?

- The results may upset you and make you feel worried or depressed.
- You may feel pressure to make hard medical decisions.
- A positive result may make you worry about others in your family.
- A positive result may cause you to worry about insurance coverage and confidentiality.

What are the risks of genetic testing for others?

- A positive result may cause stress in your relationships with other family members, your spouse or your partner.
- You may learn that you were adopted or that one of your parents is not your biologic parent.
- A negative result may cause stress in a family if there are other family members with positive results.

In addition to the impact on your health, much of the information that we talk about during your genetic counseling session relates to the medical and emotional health of others in your family. However, it is not possible for us to give medical or psychological advice to family members. It is important for you to let them know to talk to their own doctors about their potential risks and their need for care.

What do you think are the benefits and risks of genetic testing?
