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Should I Get Genetic Testing for Cancer Risk?

Genetic testing is a hot topic and can be used to learn about inherited cancer risk. (This is called predictive genetic testing.) But there are many things to think about **before** you do it. If you have any [indications](#)¹ that suggest you might benefit from testing (such as certain diseases or patterns of disease), talk with your health care provider and plan to meet with a genetic counselor so you know what to expect.

Here are some of the things you should discuss and consider before testing.

What might you learn from genetic testing?

The obvious benefit of genetic testing is the chance to better understand of your risk for a certain disease. It can help ease uncertainty. Testing is not perfect, but it can often help you make decisions about your health.

For families at risk, a negative result on a genetic test for a certain kind of cancer may help ease anxiety. In the same way, a positive result can help you make important decisions about your future, including things you can do that might help lower your risk. A positive result may also lead your health care provider to have you:

- Start cancer screening tests earlier (if available for the cancer type)
- Get screened for that type of cancer more often
- Get screening tests that are used only for people known to be at increased cancer risk
- Watch yourself closely for signs or symptoms of that kind of cancer
- Learn about options to help reduce the risk of certain types of cancer, such as drugs or surgery

If you do develop cancer, finding it early (when the cancer is small) often means that treatment is more likely to be helpful.

Genetic testing results often give limited answers.

Genetic tests usually do not give precise answers about inherited diseases. Testing can only tell you if you have a specific gene mutation, not if you will get cancer. A positive test result does not always mean you will get the disease. The test can tell what *might* happen, but it cannot tell what *will* happen. On the other hand, a negative result does not mean you have no risk of getting the disease. And risk can change over time due to lifestyle choices, and simply getting older.

This is why counseling **before** testing is so important – you’ll want to know [if and how the results could help you²](#).

As with many medical tests, genetic tests may be flawed, or test results may be read wrong. This is not common, as many steps are taken to prevent this, but at this time genetic testing is not tightly regulated, and different labs may have different ways of looking for certain changes.

Sometimes the tests themselves might not give clear answers. For example, you may be found to have a certain gene mutation, but it might not be clear if this particular mutation actually raises your risk (or, if it does, by how much). Researchers are always learning more about the results of genetic testing and what they might mean, but at this time there are still many unanswered questions.

Some genetic test manufacturers advertise and promote their tests to doctors and to the public. Sometimes they can make the test sound much more helpful and decisive than it’s actually proven to be. This can be harmful because decisions about testing may be made based on incomplete information, or even on the basis of misleading or wrong information. A lot of tests don’t give the answers they seem to promise. Reputable [genetics counselors³](#) can help you know what to expect from your test results.

How might the results affect my family?

Many people are anxious even before they get their test results. They may think about how the result might affect them and their families. They may worry about how they can talk about and manage the information.

Learning that you or a loved one might have or develop a serious disease can be

frightening. The person being tested may find it even more upsetting if family members have already died of the disease in question. Having a gene or passing the gene on to children can also lead to guilt or anger.

On the positive side, if you're tested and found to have a specific gene mutation, it might help your family members decide if they, too, wanted to be tested. This might help them learn more about their own risk, and whether there are things they can do about it. Or testing might offer them some peace of mind if it turns out that the gene mutation does not run in your family.

On the other hand, not all family members might want to know if they might be at increased risk, especially if there isn't much they can do about it. Testing any family member might lead to anxiety and other concerns in other family members.

Privacy may become an issue when many family members could be affected by a single positive genetic test result. More family members may need to be tested. Sometimes family secrets are revealed as a result – paternity, adoptions, or other difficult issues may come up.

Will testing lead to more medical tests?

In some cases, more medical tests or procedures may have to be done as a result of genetic testing. For example, if a gene mutation for colorectal cancer is found, more tests like colonoscopy may be recommended.

This can be a good thing, if these other tests help keep you free of cancer or if they find it early, when it's likely to be easier to treat. But the tests can have downsides as well, such as the time and expense involved, as well as possible risks from the tests themselves. These extra tests can also lead to more stress and anxiety.

Who pays for genetic testing?

Genetic testing is complicated, and it can cost a lot. Some tests cost more than others, but the final bill can be thousands of dollars. Be sure you have an idea of how much it will cost you before you have testing done.

If you have health insurance, you'll need to decide if you're going to ask your insurance company to help pay for testing. Some people choose to pay for it themselves in order to keep the results as private as possible. For the most part, state and federal laws do not require insurance companies to pay for predictive testing, so not all of them cover the tests.

Federal health care laws say that genetic testing should be covered for some women found to be at higher risk for [breast](#)⁴ and/or [ovarian cancer](#)⁵. The amount of coverage depends on your health plan, so you have to contact them to find out what's covered.

What about privacy issues and genetic testing?

Most people who ask about the privacy of genetic information are worried about how the information could be used in ways that can harm them. Most Americans are afraid that employers and insurance companies might get and use their genetic information. The truth is, patients, families, and health care providers are not the only ones interested in genetic information. Here are some of the other groups who might want to use this information:

Medical and pharmaceutical researchers

Medical and pharmaceutical researchers are interested in low-cost access to genetic information and materials. Members of the pharmaceutical lobby have argued against people owning their own genetic information, stating it would drive up drug costs, which would be passed on to the consumer.

Today, medical researchers must get the individual's informed consent before any studies of tissue samples and DNA can be done.

Employers

Employers are allowed to ask for genetic testing only when it's used to monitor exposure to potentially toxic chemicals and substances in the workplace. Discrimination and employment decisions based on genetic information are barred at the national level for most employers.

Insurers

Federal law does not allow health insurers to use genetic information when deciding who to cover and how much to charge for insurance. But the law does not restrict use of genetic information for life insurance, disability insurance, or long-term care insurance.

Could the test results lead to discrimination?

Some people fear an employer could find out about the results of their genetic test and discriminate by not hiring or promoting them. Some are even concerned that adoption

efforts could be stopped based on a potential parent's genetic information.

Before you decide on testing, it's important to think about who might learn about your results and with whom you will share your results.

GINA (Genetic Information Nondiscrimination Act of 2008)

GINA is a federal law that prohibits the use of genetic information in workplace employment decisions for non-governmental organizations with more than 15 employees. This law also bars health insurers from making coverage or cost decisions based on genetic information.

GINA defines genetic information as:

- A person's genetic test results
- The genetic test results of family members
- If one or more family members are known to have a genetic disease or disorder

Employers: GINA bars employers from discriminating on the basis of genetic information in hiring, firing or layoffs, pay, or other personnel actions such as promotions, classifications, or assignments. The law applies no matter how they got the information.

Employers are not allowed to require genetic testing and can't collect genetic information except for very limited exceptions. For instance, it may be allowed when information is needed to meet the requirements of [family and medical leave laws](#)⁶ or to watch for harmful effects from hazardous workplace exposures.

Employers must keep genetic information confidential. They can't release or share genetic information except when:

- The employee asks them to
- Fulfilling a request from a health researcher
- Complying with medical leave law
- Disclosing or reporting to a public health agency

Health insurers: GINA bars health insurers (including group health plans, individual plans, and Medicare supplemental plans) from turning down people or charging higher premiums for health insurance based on genetic information or for using genetic services. This includes genetic counseling and testing. The law also bars these insurers

from asking for or requiring genetic tests. GINA applies to all health insurance plans (including federally regulated ERISA plans, state-regulated plans, and private individual plans).

More details about GINA: A few states have stronger laws than GINA. GINA does not replace state laws against genetic discrimination that are broader in scope. Rather, GINA establishes a national baseline protection while allowing states to impose stronger protection.

GINA's protections do not apply to life insurance, disability insurance, or long-term care insurance. It also doesn't require health insurance to cover genetic testing.

GINA does not apply to very small employers (with fewer than 15 employees), nor does it apply to military health plans, the Veterans Administration, or the Indian Health Service. GINA does not apply to federal employees who get health coverage through the Federal Employees Health Benefits Plans.

What about home-based genetic testing?

Some companies advertise and promote their at-home genetic tests to doctors and to the public. Sometimes they can make the test sound much more helpful and conclusive than it's actually proven to be. This can be harmful because decisions about testing may be made based on incomplete information, or even on the basis of misleading or wrong information. A lot of tests don't give the answers they seem to promise.

The tests should not be used as a substitute for [cancer screening](#)⁷ or [genetic counseling](#)⁸ that may be recommended by a medical professional based on your risk for cancer. Always consult with your doctor if you are considering or have questions about genetic testing. There can be problems if genetic test results are used without consulting a medical professional. Trained [genetic counselors](#)⁹ can help you know what to expect from your test results.

Hyperlinks

1. www.cancer.org/cancer/cancer-causes/genetics/understanding-genetic-testing-for-cancer.html
2. www.cancer.org/cancer/cancer-causes/genetics/understanding-genetic-testing-for-cancer.html
3. www.cancer.org/cancer/cancer-causes/genetics/understanding-genetic-testing-for-cancer.html

4. www.cancer.org/cancer/breast-cancer.html
5. www.cancer.org/cancer/ovarian-cancer.html
6. www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/health-insurance-laws/family-and-medical-leave-act.html
7. www.cancer.org/healthy/find-cancer-early.html
8. www.cancer.org/cancer/cancer-causes/genetics/understanding-genetic-testing-for-cancer.html
9. www.cancer.org/cancer/cancer-causes/genetics/understanding-genetic-testing-for-cancer.html

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