

THE GENES BETWEEN US:

Your guide to sharing genetic test results
with relatives



FORCE

Facing Hereditary Cancer EMPOWERED

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Have you had genetic testing for an inherited gene mutation linked to cancer?

If so, the nonprofit organization, Facing Our Risk of Cancer Empowered (FORCE) wrote this guide to help you share your test results and other health information with your relatives. As part of the sharing process, we hope that you will give copies of this guide to your relatives, who in turn will discuss the information with their doctors to make informed decisions about their medical care.

This guide is meant to be a resource for people and families affected by cancer. The guide should not be used as medical advice.



PREPARING TO SHARE

Expert guidelines for genetic counseling and testing

According to experts, anyone who has a blood relative with a known cancer-causing inherited mutation should be referred for genetic counseling and testing. This means that if you tested positive for a mutation linked to hereditary cancer, your blood relatives also qualify for genetic testing. Contacting all of your relatives may seem like a daunting task, but looking at your family tree may help you to narrow down the list of relatives who should be informed, and resources are available to help you.

Expert guidelines recommend that people meet with a genetics expert before and after genetic testing. A pre-test genetic counseling appointment can help people understand all the facts they need about the benefits and limitations of testing and clarify their medical options to make informed decisions about whether or not to proceed with genetic testing.

Why should you share?

- Inherited gene mutations affect men and women across multiple generations within families.
- Blood relatives, even distant relatives, may share the same mutation that runs in a family.
- Your relatives may not be aware of your family's medical history.
- Your relatives may not be aware of genetic testing for cancer risk.

- If you have had genetic testing, you may be in a position to provide your relatives with information that they can use to understand and manage their risk for cancer.

Experts believe that most people who have an inherited mutation are unaware and have not had genetic testing. For this reason, many genetics experts emphasize how important it is for people with an inherited mutation to share this information with all of their blood relatives.

Your genetic test results may provide relatives with important clues about their own risk for cancer.

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I had testing after my diagnosis of breast cancer. When I reached out to my cousins about my genetic test results, I learned that they already knew about the mutation in the family. I was disappointed that no one had reached out to me before I was diagnosed with cancer.



I was afraid that the timing was not right to tell my daughter about her risk.

Sharing your results can benefit your relatives in the following ways:

- Your test results can help your relatives make informed decisions about whether or not they wish to have genetic testing.
- Your results can help your relatives' healthcare providers decide if genetic testing is appropriate and if so, which test to order.
- If you carry a mutation and a genetic test shows that your relative does not have that mutation, their risk for cancer may not be elevated.
- If you carry a mutation and your relative tests positive for the same mutation, they will gain valuable knowledge about their risk for cancer. This may allow them to take steps to lower their risk for cancer or detect it at a more treatable stage. Such action may include counseling and cancer screening.

If you decide not to share

- If you feel that sharing your test result is a burden to your relatives, remember that keeping the information from them will not change their risk for cancer, and it may limit their options for early detection or prevention.
- You may have valid reasons to delay telling relatives until the timing is right. However, although there is no perfect time to learn about the risk for cancer, there is also no convenient time to receive a diagnosis of cancer.

Which relatives are at risk?

If you tested positive for an inherited mutation, it came from either your mother or your father. Knowing which side of the family your mutation

came from, you can focus your efforts on informing relatives on that side of the family. However, if you are uncertain which parent passed the mutation on to you, and your parents are unable to be tested, you may have to inform relatives on both sides of your family. Patterns in your family medical history may help you identify which side of your family is the likely source of the mutation. The genetic counselor or doctor who ordered your genetic test can help you narrow down your list. You may also be able to enlist relatives to help you tell other relatives.

Telling young adults and minors

Expert guidelines outline the best age to begin cancer screening and prevention for each gene mutation. The cancer risks and expert recommendations vary by gene mutation and family history.

Most inherited gene mutations do not increase cancer risk in children. For these genes, experts typically recommend waiting until after age 18 before deciding about testing. However, some genes may be linked to childhood cancers; in these situations, it is appropriate for children to be tested. It is most helpful for people to learn about the mutation in their family by the time they reach the recommended age to begin screening and prevention. Speak with your healthcare provider to learn the recommended screening and prevention guidelines for your particular mutation.

Even though genetic testing is not generally recommended for minors, some parents may prefer to talk to their children about the cancer in the family. FORCE and the National Society of Genetic Counselors created a guide (FacingOurRisk.org/Telling-children) to help parents have a conversation about hereditary cancer with their minor children.

After I told my cousin, she notified all her siblings so I didn't have to.



Expert screening and prevention guidelines

For people with an inherited BRCA1 or BRCA2 mutation, screening and prevention guidelines begin at age 25 for women and age 35 for men. Screening may be recommended at an earlier age for families with very early-onset cancers.

For people with an inherited mutation in a gene associated with Lynch syndrome, screening and prevention beginning between the ages of 20 and 25 are recommended. Recommendations begin at a younger age for some genes that are associated with earlier onset for cancer. Guidelines recommend that individuals who have mutations in other genes including TP53 (associated with Li-Fraumeni syndrome), PTEN (associated with Cowden syndrome), and STK11 (associated with Peutz-Jeghers syndrome) should begin screening before the age of 25.



“I had testing at 17. I felt mature enough to make my own informed decision. I knew that it would not affect my medical care until my 20s, but I was glad to have the information ahead of time. Ten years later, I have no regrets.”



WHAT SHOULD YOU SHARE?

Sharing medical information

Your medical records are very personal. Not everyone is comfortable sharing health information with other people, even relatives. **If you are open to sharing, parts of your medical records may be helpful to your relatives, including the following information:**

- **Your cancer type**

Certain cancer types and even subtypes are more closely linked to genetic mutations than others. If you have been diagnosed with cancer, sharing your pathology results may provide your relatives and their healthcare provider with additional clues about their risk, access to certain screening procedures, or eligibility for screening clinical trials.

- **The type of genetic test you had**

Different genetic tests look for mutations in different genes. Knowing which test you had can help your relatives' doctors understand which genes were tested and which genes were not.

- **Your test results and report**

Sharing your genetic test report can be very helpful to your relatives. Genetic testing laboratories provide results that identify the gene (e.g., BRCA2, PALB2, CHEK2, MSH2, or others), list the type of mutation found (if the test is positive), and the location on the gene where the mutation was found. Sharing this information can help assure that your relatives' doctors order the proper test.

Even if you test negative for a genetic mutation, your relatives may still be at risk for having a mutation. Your negative results are especially relevant for your children.

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My cousin's genetic test results helped me get a referral for genetic testing. But it was the information about his pancreatic cancer diagnosis that gave me access to a pancreatic screening clinical trial. I am so grateful!

Getting your medical records

You have a right to all your medical information, including your genetic test results and tumor pathology report. Most genetic counselors will provide you with a copy of your genetic test results for your records. Many hospital systems keep patient records in electronic form and make them available to patients to print or download through a patient portal. If you have a patient portal but the report you are looking for is not there, request that your doctor's office "release the report to your patient portal." Some genetic testing laboratories also have patient portals that allow you to download your genetic test results.

If your healthcare provider doesn't have a patient portal, you may request printed copies of your records. Providers may charge a small fee for printed copies of your records.

Sharing the name of a genetic counselor

Guidelines recommend genetic counseling with an expert in cancer genetics before and after genetic testing. You can help prepare for a conversation with your relatives by having the name of a genetics expert in their area. The National Society of Genetic Counselors (NSGC.org) has a "find a counselor" tool that allows you to find genetic counselors by location and specialty—choose "cancer" as the specialty area. Some genetics experts offer genetic counseling by phone, which is particularly helpful for relatives who may live in rural areas or who may not be able to travel to see a genetic counselor. You can also refer your relatives to **FORCE's toll-free helpline at 866-288-RISK, ext. 704**. A board-certified genetic counselor will answer general questions and help

TIP:

In a FORCE survey on sharing genetic test results within families, people who received the name of a genetic counselor from a relative were more likely to be satisfied with how they were told about the mutation in their family.

them find the closest counselors in their areas.

Gathering facts and resources

Medical decision-making is personal and not everyone is the same. Some people like detailed information, while others just want the basics. Some people may decide to do their own research; others might be satisfied with the information that you supply. Although some family members may make up their minds about testing on the spot, others may need time to process what you tell them. Whatever their preference, you can provide your relatives with the tools to help them make an informed decision. The rest is up to them. Try not to overwhelm your relative with information. Sometimes connecting them with a genetics expert in their area is enough to get them started on the path that is right for them.

You don't need to be an expert in genetics to provide your relatives with basic information about genetic testing. Guiding them to a cancer genetics expert and credible resources may be the single most important thing you do. Still, some people feel more comfortable having a conversation with relatives when they are armed with their own set of facts.



After telling my uncle about my genetic test results, he went for testing with no genetic counseling and told me he was negative. I later learned he had only tested for the three mutations common in Jewish people. We are not Jewish and he was not tested for the mutation I carried. After that I shared my full results with him so that his healthcare provider could order the correct test for him.

Visit the [FORCE](https://www.force-uk.org/) website or speak with a genetics expert for facts about the following topics.

- **Cancer risks associated with your gene mutation ([FacingOurRisk.org/Genes](https://www.facingourrisk.org/Genes))**
Different genes are associated with different cancer risks in men and women, and these risks vary by mutation. Mutations have been linked to increased risks for several cancers, including breast cancer in women and men, colorectal, ovarian, pancreatic, prostate, uterine cancers, and melanoma.
- **Guidelines for cancer screening and risk reduction ([FacingOurRisk.org/Guidelines](https://www.facingourrisk.org/Guidelines))**
Options for cancer screening and risk reduction vary by gene mutation. Panels of experts create guidelines based on the latest research and update them regularly.
- **Targeted treatment options for people who are diagnosed with certain hereditary cancers ([FacingOurRisk.org/Treatment](https://www.facingourrisk.org/Treatment))**
Treatment options known as “targeted therapies” may be available for treating certain types of hereditary cancers.
- **Laws related to genetic privacy, discrimination, or insurance coverage ([FacingOurRisk.org/Laws](https://www.facingourrisk.org/Laws))**
Federal and state laws protect people who test positive for a genetic mutation. Laws about health insurance coverage for certain types of genetic testing, screening, and treatment are also in place.
- **Clinical trials and research studies ([FacingOurRisk.org/Research](https://www.facingourrisk.org/Research))**
Research studies are looking at new options for detecting, preventing, and treating hereditary cancers.
- **Support resource ([FacingOurRisk.org/Support](https://www.facingourrisk.org/Support))**
[FORCE](https://www.force-uk.org/) and other organizations offer in-person and online support and conferences for people who are affected by hereditary cancer.

MYTHS AND MISINFORMATION

Common myths about genetic testing include the following:

Myth: Only women can carry an inherited mutation associated with cancer risk.

Fact: Both men and women can inherit a genetic mutation associated with cancer.

Myth: Only women with mutations are at high risk for cancer.

Fact: The increase in cancer risk varies by gene. The most common gene mutations increase the risk for cancer in both men and women.

Myth: People who test positive for a genetic mutation are at risk of losing their health insurance.

Fact: Laws protect people from health insurance and employment discrimination.

Myth: Genetic testing is very expensive and is not covered by insurance.

Fact: The cost for genetic testing has gone down, and testing is more affordable than ever. Testing is covered by most insurance companies, especially for people who have a relative who tested positive. Testing options are also available for people who are uninsured. Additionally, reputable laboratories offer financial assistance or low-cost testing for people whose testing is not covered by insurance.



MAKING CONTACT

Degrees of relatedness

When speaking about a family tree, experts use the term “degree of relatedness” to describe how closely a family member is related to you. When experts speak about “first-degree relatives,” they are referring to relatives who share half of your DNA and who have a 50 percent chance of testing positive for the same mutation that you carry. Importantly, if your mother or father tests positive for a mutation, then you and each of your siblings have a 50 percent chance of also testing positive for the same mutation. Even if you test negative, your siblings need to undergo testing to determine if any of them have your parent’s mutation.

First-degree relatives

- Siblings
- Children
- Parents

Second-degree relatives

- Half-siblings
- Uncles and aunts
- Grandparents
- Grandchildren
- Nieces and nephews

Third-degree relatives

- Cousins
- Great-grandparents
- Great-aunts and great-uncles

Who to contact first

Drawing your family tree can help you identify which relatives to tell first about your genetic test results. Some family members who are particularly close and more up-to-date on family happenings may be willing and able to help you locate and discuss your test results with your extended family.

If a relative tests negative for the mutation in your family, his or her children will not benefit from testing for that mutation. For example, if your aunt tests negative for your mutation, her children (your cousins) do not need to be tested. If your brother tests negative, his children (your nieces and nephews) will not carry your mutation. They could still develop cancer, but their risk may be the same as someone who does not have a mutation.

Contacting male and female relatives

It is important to notify both your male and female relatives about genetic test results. Men can carry gene mutations; men with mutations have increased risk for different cancers. The type of cancer they are at risk for depends on the gene mutation. Certain mutations can increase the risk for pancreatic, prostate, male breast cancer, colorectal cancer, melanoma, and stomach cancer to name a few. Visit the FORCE website to find a list of gene mutations and their associated risks.



I did ancestry testing and was contacted by someone who was identified as my second cousin. I felt it was important to tell her about the mutation in the family. I was glad that I did because she had not been aware of it and pursued testing after I told her.

My Aunt Jenna is the family historian. She has meticulously collected our family story. Before I contacted any other relatives, I reached out to her for help in reaching distant relatives. I was so glad that I did. She helped me create a list and reached out and notified several relatives who I had lost contact with.

I have been estranged from my father's side of my family, so I was grateful when my cousin reached out to me and told me about his genetic test results.

Planning the communication

How you notify relatives about your genetic test results is up to you. Some people use the same approach for all their relatives, while others prefer to tailor the conversation for each relative. Understanding your relatives' situation can help you prepare for their reaction to your news.

Here are some things to consider:

- Are they being treated for cancer? If so, genetic testing may affect their surgical decisions or open up new options for treatment or access to clinical trials.
- Do they have any physical, language, or financial challenges or barriers to receiving care? Specific resources to help overcome these barriers, including programs that offer financial support for genetic testing or high-risk screening, may be available.
- Do they have adult children whom they will need to inform? Are they close with other relatives? If so, they may benefit from having additional copies of this guide.
- Do they live near a cancer center with expertise in caring for people who are at high risk for cancer? Often larger cancer centers or those affiliated with universities have more resources for supporting people interested in learning more about genetic risk and testing. National Cancer Institute (NCI)-designated cancer centers always have such resources available.
- Are there specific guidelines for risk management for their age, gender, and circumstance?
- Have they lost close relatives to cancer? Was this loss recent? This may affect how they respond to your information.

TIP: In FORCE's survey on family sharing of genetic test results, people who were informed of a family mutation by text or Facebook were less likely to be satisfied than people who were told in person or by phone, letter, or email. Nevertheless, most respondents were grateful to their relatives for telling them about the mutation in their family.

Technology allows us to reach out and communicate with relatives in a variety of ways. Each method has benefits and limitations.

- For relatives with whom you are close, an in-person meeting allows physical touch and reassurance.
- Family reunions, holiday gatherings, or weddings may provide the opportunity to collect contact information from multiple relatives in person, including those whom you may not frequently speak with or see.
- Although less intimate, a video chat allows you to gauge relatives' expressions and provide support and comfort as needed.
- Some people are uncomfortable with emotional in-person or video meetings. You may have relatives who prefer privacy or who need time to process personal information in their own time. An email, letter, or phone call may be the best or easiest way to contact these relatives.

Reaching relatives with whom you are not close

Everyone feels closer to some relatives than others, and in some cases, members of your family may be estranged. Family issues can make these discussions more awkward or difficult. There is no single correct way to communicate this information. You may find that you communicate differently with different relatives and that's okay! You can also ask family members with whom you are more comfortable to help—they may not mind sharing the information with other relatives for you. Family sharing is a process, and it can take some time and thought to figure out how to approach it.

Beginning the conversation

Sometimes the hardest part is knowing where to begin. A good place to start may be to share how you first learned about genetic testing, why you decided to be tested, or who else in the family has had genetic testing. You might outline what you have learned about your family history, including who was diagnosed with cancer, the type of cancer they had, and how they are related to you.

Range of reactions

Everyone processes health information and health threats differently. Genetic test results come with the added burden of risk to children and loved ones. Your relative may not respond to your contact in the way you expect.

Possible reactions may include:

- Anger
- Confusion
- Denial
- Disbelief
- Fear
- Gratitude
- Guilt
- Resentment
- Sadness

As your relative listens and responds to the information you are sharing, it can be helpful to assess your own feelings. After all, the genetic information you are sharing affects you too. Try not to take your relatives' initial reactions personally, even if their response feels personal or insensitive.

You do not need to shoulder your relatives' emotions alone. If a relative lashes out, you can tell them that you are ending the conversation. If you wish, you can invite them to reach out to you after they have had a chance to calm down.

If you find yourself becoming overwhelmed, it's okay to tell them and then take a time-out. You might say, "This conversation is hitting close to home for me. I know that I have given you a lot to think about. Perhaps you can call a friend or visit FORCE to discuss your thoughts and concerns with trained volunteers."

Your relatives' reactions may change as they have a chance to process the information and learn more about genetic testing. Try not to manage or fix your relatives' feelings, but instead give them the space to feel.

