Sharing Genetic Test Results With Your Family [1]

This section has been reviewed and approved by the Cancer.Net Editorial Board [2], 03/2012

Key Messages

- If you undergo genetic testing to learn more about your risk for a specific cancer, it is important to tell family members about the information you have learned.
- The way you share this information with each family member depends on the closeness of your relationship.
- Not all family members, though, may want to know your test results or share your enthusiasm for knowing more about their health and cancer risk.
- Talk with a genetic counselor to get suggestions about how best to best talk with your family members about your test results and what specific medical information you should share.

People with a strong family history of cancer may meet with a genetic counselor and choose to receive specific genetic tests as a way to learn about their risk of cancer. In fact, many people choose to have genetic testing [3] so they can share risk information with their family members. However, it is important to be aware that the results of these tests will have implications for your family members. For example, your child or sibling may learn that they could be at increased risk for specific types of cancer. It is for this reason, if you choose to undergo genetic testing, that you are strongly encouraged to tell your relatives the results. Even if the result is negative, meaning you do not have a gene mutation, you should share this result. The genetic counselor [4] can help you with this process.

Your genetic test results

If you test positive for (meaning that you carry a cancer susceptibility gene mutation), you have a greater than average risk of developing cancer. If you have already been diagnosed with cancer, you may have an increased risk of developing other cancers as well. Learn more about cancer risk [5].

When you receive the results, your genetic counselor will discuss the meaning of a positive test result for both you and your family members. If your family has already discussed their cancer history and genetic testing, you may find that sharing test results with them is easier. In some situations, you may want to bring a family member with you to learn the results so that there is another person in the family who can help share the test results. You may want to discuss your

plans for sharing the results before you receive them.

When first hearing the results, a person who tests positive for a gene mutation may feel grief, anger, anxiety, depression, and/or guilt at possibly passing the mutation to his or her child. However, you may also experience relief at identifying a reason for the cancer in the family and empowerment to make medical decisions to lower your cancer risk.

Sharing positive test results with adult family members

How you choose to discuss test results with family members depends on your comfort level and relationship with each family member. For example, for distant relatives, a letter might be a good approach. For closer relatives, you may consider a phone call or face-to-face meeting. However you choose to communicate you test results, the genetic counselor can help you share the information in the way that is most comfortable for you.

The two important scientific pieces of information to share with family members are:

- The specific gene where the mutation was found, because many hereditary cancer syndromes are linked to more than one gene
- The specific mutation; gene mutations are commonly given a combination of numbers and letters, such as the 187delAG mutation in the *BRCA1* gene.

This information is what a laboratory will need to test your family members. It is helpful to provide family members with a copy of your test report so they can take it with them if they choose to have genetic testing.

What family members choose to do with the information

Relatives who are at risk for having an inherited gene mutation are encouraged to talk with their doctor and meet with a genetic counselor to discuss their cancer risk. A genetic counselor can review cancer screening [6] guidelines and discuss the risks, benefits, and limitations of genetic testing. Your genetic counselor, doctor, or other healthcare professional may be able to help you find qualified genetic professionals near your family members and provide written information to share with your family. Two resources are National Society of Genetic Counselors [7] and National Cancer Institute Genetics directory [8].

People who test positive for a gene mutation may feel empowered by having information about cancer risk that past generations did not have. They may strongly encourage other family members to be tested for this gene mutation. However, not everyone's reaction to genetic testing is going to be the same, and not all relatives who are at risk will immediately want to have testing, or even know your results. Some family members may feel that knowing the results will make them more anxious about the risk of cancer. Parents may feel guilty about possibly having passed on an increased cancer risk to their children and not want to have that possibility confirmed. Other family members may feel bad if they do not have the gene mutation and are spared this increased cancer risk when their family member was not. Close family members (siblings, children, parents) should be given recommended cancer screening guidelines and follow the recommendations for people who have a high risk of the cancer until they learn their own genetic testing results.

It is important to be supportive but not pushy when talking to relatives about genetic testing. Everyone should be given the opportunity to undergo testing and to make his or her own decision about whether to be tested.

Sharing positive test results with children

Only a few known hereditary cancer syndromes increase the risk of cancer in children. These include familial adenomatous polyposis (FAP) [9], multiple endocrine neoplasia (MEN) type 1 [10] and type 2 [11], and von Hippel-Lindau syndrome [12] (VHL). If a person in a family tests gene mutation positive for one of these disorders, it is important for the children at risk to have genetic testing. Children who test positive for the mutation will need to begin cancer screening while they are still children (sometimes as young as infants). Children who test negative for the gene mutation can be spared invasive medical procedures.

It is important for you to try to explain to your child, according to their age and maturity level, why he or she needs to have testing. It is also important to let your child know what to expect, since genetic testing involves drawing blood. A genetic counselor and a medical geneticist (a doctor with training in genetic diseases and conditions) can help you talk with your child about genetic testing and the specific condition in the family. For some conditions, there may be printed materials designed especially for children.

Testing children or adolescents for hereditary cancer syndromes that cause cancer in adults is not recommended. It is important, however, to answer any questions about the family history as openly and honestly as possible. As your children grow older, they may have questions about the family history of cancer. They can be reassured that, despite the family history, there are steps they may be able to take to lower their cancer risk.

Sharing negative test results with family members

If you receive a negative test result, meaning that you do *not* have a specific gene mutation, your genetic counselor will help you understand what this means for you and your family. You may be relieved to know this specific type of cancer does not run in your family. Or, you may be left with more questions if it seems like there has been a high incidence of cancer in the family. After a negative test result, not everyone in the family needs to have genetic testing, especially if they do

not have cancer and there is no reason to suspect a genetic basis for cancer. In this situation, testing of an unaffected family member will not yield additional information.

More Information

The Genetics of Cancer [13]

Hereditary Cancer-Related Syndromes [14]

Direct-to-Consumer Genetic Testing [15]

Last Updated: March 26, 2012

Links:
[1] http://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/sharing-genetic-test-results-your-family
[2] http://www.cancer.net/about-us
[3] http://www.cancer.net/node/24895
[4] http://www.cancer.net/node/24907
[5] http://www.cancer.net/node/25007
[6] http://www.cancer.net/node/24972
[7] http://www.nsgc.org
[8] http://www.cancer.gov/cancertopics/genetics/directory
[9] http://www.cancer.net/node/18852
[10] http://www.cancer.net/node/19366
[11] http://www.cancer.net/node/19365
[12] http://www.cancer.net/node/19322
[13] http://www.cancer.net/node/24897
[14] http://www.cancer.net/node/24905
[15] http://www.cancer.net/node/24382