

Informing adult family members about your BRCA1 or BRCA2 genetic test results

If you recently tested positive for a mutation in your *BRCA1* or *BRCA2* gene, you may wish to inform your family members. This is because they may have inherited this same genetic mutation that puts them at an increased risk for breast, ovarian or other associated cancers. Sharing this news with your family is not always easy, due to the unique dynamics that exist in every family. Mixed emotions and reactions may arise when learning of an elevated cancer risk.

Here are some suggestions to consider when sharing your test results with your adult family members.

When do I tell my family members?

First, take some time for you. After learning your own test results, take time to digest the information and work through your own emotions. You will be more prepared to share your results with others if you have done this beforehand.

Make a plan. Before sharing the news with other family members, carefully consider who you will be talking to, where and how this communication will take place and the ways this news may impact family relationships. Having a plan can decrease anxiety by giving you more control over the situation.

Who in my family should I tell?

Identify at-risk family members.

Determine ahead of time who in your family will be receiving this information. Your genetic counsellor is trained to help you identify at-risk family members. When you are ready, it may be easier to start by discussing your results with family members with whom you feel most comfortable. If you do not feel comfortable being the one to share the news, you may want to consider asking another family member to communicate this information on your behalf.

Inform both female and male relatives.

Both men and women can carry a *BRCA* gene mutation and be at increased risk for the associated cancers. Those who carry it have a 50/50 chance of passing it on to their sons or daughters. Therefore, it is important for all at-risk adult family members to be informed. Parents who do not have the *BRCA* gene mutation cannot pass it on to their children.

Those at-risk in your family may include:

- children
- brothers and sisters
- parents
- grandparents
- aunts or uncles
- cousins

How will I communicate this information?

Determine your method. Choose a communication method that makes the most sense considering your family dynamics, communication styles and geography. You can offer the facts via a face-to-face meeting, letter, email or phone call.

Arrange a meeting. Although there is never a good time to communicate difficult news, if you choose to meet with relatives in person, carefully choose a time and place.

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Request that your family members set time aside to speak with you. Ask a friend or other relative to be there for support, if needed. While a family gathering may be an efficient way to spread the information, it may sometimes be an awkward or unexpected place to give and receive such news. However, if you and your family members already find support in each other, or other family members have already raised the topic, a family gathering may be a good place for such a discussion.

Pick up the phone. If meeting face-to-face isn't possible, it may be easiest to communicate your news over the phone. Establish a time that is convenient for both you and your family member. Arrange to make the call from a quiet place where you will not be disturbed.

Use a letter. You may feel most comfortable sharing the information by writing a letter or email, especially if you are not close with your relatives or find it difficult to speak about this. A letter could be used as an introduction to the history of cancer in your family or as a follow-up to conversations you had with relatives in person or by phone. Your letter can invite them to contact you or your genetic counsellor for more details. A sample letter to use as a guide is available through Willow; your genetic counsellor may also have one.

What do I tell my relatives?

Give them the facts about your genetic test results. Be sure to tell relatives which gene was involved (*BRCA1* or *BRCA2*) and the specific mutation that was found (such as the 5382insC mutation). This information is necessary if they want to get their own genetic testing done. It may be easiest to communicate this information by providing them with a copy of your own test results.

Be prepared for questions. Learning about a possible health condition raises many questions for people. If you find it intimidating to explain hereditary breast and ovarian cancer, it may be helpful to have some printed factual information on hand. Remember, you will likely know a lot more about hereditary cancer than your relatives. It may take some time for them to understand this information. For this reason, it's often best to provide only the basic details in your initial conversation. If you are comfortable, you may want share your personal experience about being tested.

When talking to relatives, be prepared to answer questions such as:

- What is hereditary cancer?
- What does a *BRCA* mutation mean for me and/or my children?
- How do I get tested?
- Who else in the family could carry this gene mutation?

For basic information about hereditary breast and ovarian cancer, see the "Additional Resources" section at the end of this fact sheet.

Genetic counselling provides more information. If a relative wants to learn more about the inheritance of cancer in their family, genetic counselling, genetic testing or the type of cancer screening that is available, recommend they speak to a genetic counsellor. Let your relatives know that genetic counselling is a source of information, but not a commitment to genetic testing. Whether or not a family member chooses to be tested, a genetic counsellor can arrange available high risk cancer screening procedures such as a breast MRI.

What can I expect?

Be prepared for different emotions.

When discussing your genetic test results with family members, you or others may experience several emotions such as guilt, anxiety, relief, sadness, anger, resentment, frustration or empowerment. This is natural, especially when discussing such a difficult topic with close family members. Some family members may appreciate being advised of your test results, while others may not. Some may even be angry that you had the testing in the first place and shared your results since it forces them to confront a difficult issue.

My relatives are interested in genetic counselling.

- You can provide them with the contact information for your genetic counsellor (your information remains private and confidential).
- You can provide them with your test results, as this will help with their genetic counselling appointment.
- They can ask their family doctor for a referral to the nearest genetics clinic.
- They can directly call a genetic clinic in their area. (See Additional Resources)
- Your genetic counsellor or Willow can also assist with contact information for genetic programs throughout the country.

Be prepared for different reactions. Some family members may want to know more about the gene mutation and genetic testing while others may refuse any more information at this time. Both reactions are normal and acceptable. Give family members the time and space they need to understand and process your news.

There is no right or wrong way to tell someone about your test results. These are only meant to be suggestions. Do what feels right for you. Most family members will understand that you had the best intentions in deciding to share your genetic test results.

Be aware that family dynamics may change.

A topic such as cancer risk has the potential to affect your relationships with family members. After sharing your news, you may feel closer to family members. You may feel a deeper bond with relatives based on your shared genetic risk. Alternatively, you may feel more isolated from relatives after sharing your test results, particularly if they react in a way that you find upsetting.

Get support from others.

You or your family members may find it helpful to seek support from other people you trust who are not biologically related to you. Your support system may include:

- partner/spouse
- friends
- colleagues
- doctor
- mental health professional
- religious or spiritual leader
- Willow Breast Cancer Support Canada

You may also benefit from connecting with others who are going through a similar experience. A support group may be available where you live. There are also online support communities or discussion boards on the Internet that you may find helpful. Contact Willow to find a support group in your area.

Additional Resources

For more information about hereditary breast and ovarian cancer, the following organizations may be helpful to you:

Willow Breast Cancer Support Canada
In Our Genes Program
1.888.778.3100, www.inourgenes.ca

HBOC Hereditary Breast and Ovarian Cancer Society of Alberta
1.866.786.HBOC (4262), www.hbocsociety.org

Hereditary Breast + Ovarian Cancer Foundation (Montreal)
514. 482.8174, www.hboc.ca

Canadian Cancer Society
1.888.939.3333, www.cancer.ca (see Prevention/Family Genetics)

Facing Our Risk of Cancer Empowered – FORCE
1.866.288.7475 (USA only), www.facingourrisk.org

Be Bright Pink
www.bebrightpink.org

For Genetic Counselling and Testing in Canada and the United States:

Canadian Association of Genetic Counsellors
905.847.1363, <http://www.cagc-accg.ca/>

National Society of Genetic Counselors, Inc. (USA)
312.321.6834, www.nsgc.org

References

Cancer.net – American Society of Clinical Oncology
“Sharing Genetic Test Results With Your Family” (July 2009; accessed June 2010)
www.cancer.net/patient/All+About+Cancer/Genetics/Sharing+Genetic+Test+Results+With+Your+Family

Breastcancer.org
“Getting Genetic Test Results” (March 2009; accessed June 2010)
http://www.breastcancer.org/symptoms/testing/genetic/get_results.jsp

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