How Do I Tell My Children About My Cancer Gene Mutation?
Knowing that you have a mutation or change in a gene that may lead to cancer can raise many thoughts, questions, and feelings for you, especially as it relates to your children. You may find yourself asking, “Do I tell my children they are at risk? When do I tell them? How do I tell them? What do I do once I tell them?”

There is not a one-size-fits-all answer to these questions. In this guide, we will help you feel more comfortable and prepared to share information about genetic risk with your family. As a parent, you know your child best. Every child is different and it is important to recognize that each conversation is unique. You might think about whether to communicate all of the genetic information at one time. Discussing genetic risk is an ongoing conversation that evolves as children go through different life and developmental stages.

One in 40 Ashkenazi Jewish men and women are carriers of a BRCA gene mutation. This is more than 10 times the rate of the general population, making Jewish families significantly more susceptible to hereditary, or in other words inherited, breast cancer and ovarian cancer. BRCA gene mutations have also been found in Jews of Sephardi descent, as well as in individuals of all ethnic origins. Both men and women can carry a BRCA mutation and will have a 50% chance of passing it on to each of their children. Not everyone who inherits the mutation will develop breast cancer or ovarian cancer, but the risk is increased.\(^1,2\)

For those carrying mutations, the risk for breast cancer may reach up to 85% and up to 44% for ovarian cancer, compared to the average woman’s breast cancer risk of 12% and 1%-2% for ovarian cancer. In addition to the BRCA gene, there are other genes that, when mutated, may lead to breast, ovarian, or other types of cancer, including CHEK2, PALB2, CDH1, ATM, PTEN, TP53, and genes associated with Lynch syndrome (hereditary colon, endometrial, and ovarian cancer) that predispose an individual to breast, ovarian, and other types of cancer. Women of Ashkenazi descent with breast cancer or ovarian cancer, and individuals with a family history of these cancers, may want to consider genetic counseling and testing.\(^1-3\)

How can you lower your anxiety about family history or genetic risk so you can take care of your emotional well-being and be a strong role model for your children as well?

Strong coping skills are the best tool for fighting anxiety. In most instances, we do not have the power to change our circumstances. You cannot change the fact that you have a family history of breast or ovarian cancer. What you can change, however, is how you think about this information. Children often look to their parents for cues on how to think about information that they are unsure how to interpret. You don’t need to hide your anxiety; children appreciate emotional honesty. Your child may feel that their anxiety is validated if they observe that their parent shares some of those same emotions.

REFERENCES
Take time to process your own thoughts
It is important to take time for yourself to understand your genetic risk and what it means for you. Allow yourself the opportunity to gather your thoughts and process your emotions. Your genetic counselor, or Sharsheret’s, can assist you in deciding what is right for you and your family. Establishing an emotional and intellectual understanding for yourself is paramount, as it will help you find the right words and responses while having this conversation with others. It is important to recognize that understanding and communicating your genetic risk and the impact on your family is a process. This may mean waiting weeks, months, or even years before speaking with your child(ren) about a hereditary mutation in your family. Children may not need to know about their risk until they are older and emotionally and developmentally mature enough to receive the information.

Consider age and life stage of each family member
Keep in mind that every family member processes information and emotions in their own way. It is important to consider the age and developmental life stage of each family member as a reference point when deciding when to disclose health information. Children carry with them their own preconceived notions, experiences, hopes, fears, and faith. Recognizing your child’s abilities and developmental stage can have a big impact on when you tell them, the words you use, and how much you choose to share about your personal experience.

Find the right time
Genetic testing is generally not performed in minors, and the recommended age for having genetic testing is not usually younger than 18. Moreover, effective breast cancer screening and medical recommendations for surveillance often do not begin until age 25, and even later for ovarian cancer. Some choose to wait until genetic testing and screening become relevant while others may choose to disclose it right away.

Find the right setting
Would your family prefer a group conversation or individual one-on-one conversations? Think about your own preference style, as well as your family’s, and use this as a starting point for framing your discussion.

Identify your family’s communication style
Some families are very open and comfortable sharing information and asking questions, while others can be more guarded and private. Identifying your communication style, as well as your family’s, can help you feel more comfortable and equipped for any questions or concerns that may arise.

Find the right words
Finding the right words can be challenging. Prior to the conversation, think about what you will say and how you will say it. It may be beneficial to practice having the conversation with someone else, such as your partner, a close friend or relative, or your genetic counselor.

Writing down notes beforehand can help you guide the conversation and remember key details you want to share. Focus on the reasons you are sharing this information; knowing this information will allow your family members to be proactive and to take appropriate steps to care for their own health and well-being.

Knowledge is power
While ignorance can be bliss, this is often not the case when it comes to health issues, where knowledge can be frightening but powerful at the same time. Emphasize to yourself and your family that with knowledge you can have the power to make changes, investigate possibilities, and feel hopeful. Brainstorm with your family about proactive choices you can make individually and as a family.

Break challenges into small, manageable pieces
Show your children how to do this by modeling through your own actions. For example, instead of conveying a message of “I need a complete solution to the issue of genetic risk in my family,” show your children how coming up with a plan for the next step is more realistic, reassuring, and helpful. For example, “I am going to set up an appointment to consult with a known specialist in the area.”

REFERENCE
SUZANNE’S STORY

“When I found out I was BRCA+, I knew I wanted to tell my children so that they would understand and be able to monitor their health—I just didn’t know how and when. I took some time and realized how important it was for me to first fully understand my own genetic risk and the implications it had on my life. After I processed my own thoughts and feelings, I felt able to speak with my children about our family’s cancer risk. As my children were 5, 8, and 11, each conversation was separate and unique. I recognized they didn’t need to know all the information at once and I was able to give each child the information that was appropriate for them at the time, knowing that we’ll have more opportunities to continue the conversations as they grow older.”

- Suzanne, Sharsheret caller

Avoid catastrophizing

Catastrophizing is defined as having the irrational belief that something is far worse than it actually is. An example of catastrophic thinking in the case of known genetic risk for breast cancer would be “I am definitely going to get breast cancer at a young age. When I do, my family will not be able to function and life for everyone will be a nightmare.” While being a carrier of a cancer-related gene mutation or having a family history of breast cancer can certainly make one think this way at times, catching yourself when you have such thoughts will be helpful to you and your son or daughter. When you become mindfully aware of your own catastrophic thinking, you can then consider other possible outcomes and more adaptive thoughts. For example, a less catastrophic thought would be, “If I am diagnosed with breast cancer in the future, it will be a challenge, but my family will be ok as I get treated.”

Incorporate positive and empowering health messages

Incorporate healthy behaviors into your family’s lifestyle as this can help to mitigate risk. Having ideas about fitness activities and nutrition on hand when you speak to your children is helpful. Brainstorm with your child about ways that fitness and nutrition can be fun for them.

Gauge how family members respond

Is your child confused? Angry? Upset? Relieved? Identifying and addressing your child’s emotional response can be a helpful tool in your conversation and moving forward. Sometimes parents and children find it helpful to have the conversation in smaller parts, which enables processing time for both sides.

Reinforce support and continue the conversation

Explain to your child(ren) that there are genetic counselors that can answer personal questions and help make decisions. Reinforce that they have support both within the family and from others outside of the family, such as social workers, spiritual leaders, or community leaders that can help to aid in decision-making as well as processing thoughts and emotions. Establish safety and openness so your child(ren) can feel comfortable revisiting the conversation and express any thoughts, fears, or emotions they may have.
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Together we can ensure that no woman or family has to face breast or ovarian cancer alone.

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Sharsheret is a Jewish national not-for-profit organization supporting women and families facing breast and ovarian cancer.