

How Do I Tell My Children About My Cancer Gene Mutation?



SHARSHERET

Knowing that you have a mutation, or change, in a gene that may lead to cancer can raise many thoughts, questions, and feelings, 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 no 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. Each conversation you have with your child(ren) will be unique. One thing you may want to consider is whether to communicate all of the genetic information at once or to spread it out over time. Like many conversations, discussing genetic risk is one that should be ongoing, evolving as children go through different life and developmental stages.

Before discussing the information with your child(ren), it is important that you understand the facts. **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 inherited breast, ovarian, male breast, pancreatic, melanoma, and prostate cancer.** BRCA gene mutations have also been found in Jews of Sephardi descent, as well as in individuals of all ethnic origins. Either parent can carry a BRCA mutation and will have a 50% chance of passing it on to each of their children. It is important to note and explain to your child(ren) that not everyone who inherits the mutation will develop cancer, but that the risk is increased.^{1,2}

For those carrying mutations, the risk of developing 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% to 2% for ovarian cancer. In addition to the *BRCA1* and *BRCA2* gene mutations, there are other genes, including *ATM*, *CDH1*, *CHEK2*, *PALB2*, *PTEN*, *TP53*, and genes associated with Lynch syndrome that may be inherited. Mutations in these genes may lead to one or more cancers including breast, colon, ovarian, male breast, pancreatic, prostate, melanoma, and uterine cancer. Men and women of Ashkenazi descent with these cancers and individuals with a family history of these cancers may want to consider genetic counseling and testing.¹⁻³

REFERENCES

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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?

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, or that you carry a genetic mutation that puts you at an increased risk. 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 concern is validated if they observe that their parents share some of those same emotions. In addition, it is important to show them that although you can't change your circumstances, you can control the narrative by speaking with your doctor, going for screenings, and taking control of your overall health.

Here are some tips and guidance for preparing for and framing a conversation with your children:

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. Give yourself the opportunity to gather your thoughts and process your emotions. Your genetic counselor can assist you in deciding what is right for you and your family, and you can also speak to a genetic counselor at Sharsheret. 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 it may have 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 and understand how it applies to them.

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's 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 and how it will impact them. Whatever their age, give your child(ren) time to understand and come to terms with your genetic results so that they can make appropriate testing and screening decisions for themselves.

Find the right time

Genetic testing is usually not recommended for those younger than age 18. Moreover, effective breast cancer screening and medical recommendations for surveillance often do not begin until age 25, and even later for ovarian cancer. Screening recommendations for men begin around ages 35 or 40. Since it is possible to use IVF (in vitro fertilization) and embryo screening to avoid passing a mutation to the next generation, you will want to discuss this with your children before they are ready to have children of their own. Some choose to wait



until genetic testing and screening become relevant, while others may choose to disclose it right away in an age-appropriate way. The idea is not to alarm your child(ren), but to empower them with knowledge to prepare themselves for the future.

Your discussions will start simply. Teach your child that we have checkups with our doctors to make sure we stay healthy. Promote healthy eating and plenty of exercise, and model these behaviors with your children by your own actions. You might eventually share that you are careful about taking care of yourself because of the cancer in other family members. Eventually, you can share about the mutation in the family, and the option for the child to be tested as an adult when they are ready.

Find the right setting

Would your family prefer a group conversation or individual one-on-one conversations? Think about your own preference, 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 own personal 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. You may want to view Kognito, an interactive video to help with communication among family members or children.

simulations.kognito.com/sharing-info-about-your-family-cancer-risk/

Knowledge is power

While ignorance can be bliss, this is often not the case when it comes to health issues. Emphasize to yourself and your family that with knowledge you can have the power to make changes, investigate possibilities, and take control. Brainstorm with your family about proactive choices you can make individually and as a family. When speaking with older child(ren), it may be helpful to have printed copies of resources (available from Sharsheret) for them to read and process on their own when they are ready.

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."

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 a 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 children. 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 I will speak with my doctors and come up with the best medical plan for myself. My family will be there to support me along the way."

Incorporate positive and empowering health messages

It is important to incorporate healthy behaviors into your family's lifestyle as this can be helpful in mitigating one's risk. Having ideas about fitness activities and nutrition on hand when you speak to your children can be helpful. Explore with your child how fitness and nutrition can be fun for them and your family.

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. It may be helpful to have the conversation in smaller parts, which enables processing time for both you and your child.

Reinforce support and continue the conversation

Explain to your child(ren) that there are medical professionals and genetic counselors that can answer personal questions and help make decisions for each person. Your children may not make the same decision that you did. How to move forward and manage one's risk is a personal decision; it is your job to explain the mutation and share what you have done to manage your risk. If their results are positive, they will have to decide how to manage that risk. Reinforce that they have support both within the family and from others, such as genetic counselors, 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.

How we can help

Sharsheret's genetic counselors are available for individual phone calls to help answer questions and prepare you to speak with your family. We can also facilitate a family conference call to address your family's unique questions and concerns. Contact Sharsheret at 866.474.2774 or genetics@sharsheret.org.





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

Concerned about breast or ovarian cancer?

We can help.



One-on-One Support

- Mental health professionals
- Genetic counselors
- Peer support
- Online 24/7 Live Chat
- Customized beauty kits
- Busy Boxes for children
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- Healthcare webinars
- Campus outreach
- Community events
- Trainings for medical professionals
- Resource booklets



Community Action

- B'nai Mitzvah projects
- Team Sharsheret races
- Young Professionals Circle
- Volunteer opportunities
- Local fundraisers

Contact us today.

All Sharsheret programs, resources, and kits are **free** and **confidential**—callers are welcome to remain **anonymous**.

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.

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