

COMMUNICATING ABOUT GENETICS WITH YOUR FAMILY

Ready to share genetic information with your family but not sure when and how to start? Looking for ways to communicate genetic risk while empowering your loved ones? Whether or not you've had genetic testing, whether you've tested positive or negative, read these tips to get started and contact Sharsheret at clinicalstaff@sharsheret.org or 866.474.2774 with your individual questions and concerns.

Before getting started: Every family is different. Identify your family's unique communication style, beliefs, value system, and coping strategies. Think about your own communication style. Many find it useful to use this as a starting point for framing your discussion about genetic risk. Explore what strategies have worked well in the past and identify the challenges that have interfered in prior interactions.

Identify who to tell: Your genetic counselor can help you identify who is at risk in your family. Generally, at-risk family members should be told first. Consider each family member's unique personality and how they may react. After family members are informed of their own risk, it may be worth considering sharing information with family members who are not at risk, to facilitate support and understanding.

Consider age and life stage of your younger family members: Genetic testing is not generally performed in minors and the recommended age of disclosure is no younger than age 18. However, effective breast cancer screening and medical recommendations for surveillance do not begin until age 25, and even later for ovarian cancer. Some choose to wait until genetic testing and screening becomes relevant while others choose to disclose right away. Your genetic counselor can assist you in deciding what is right for you and your family.

Find the right setting: Would your family prefer a group conversation or individual one-on-one conversations? In person or over the phone? Some find it helpful to discuss genetic risk in a group setting such as a family get-together or over the holidays. Others prefer to be told privately. Think about each family member's communication style and what has worked in the past.

Practice makes perfect: Sometimes, finding the right words can be challenging. Think about what you will say and how you will say it. A close friend or family member,

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who knows your situation, or even your genetic counselor, can assist you in practicing this conversation. Jotting down notes prior to the conversation may be useful.

Be positive: Focus on the reasons you are sharing this information. Knowing this information will allow your family to be proactive and take appropriate steps to care for their own health and well-being.

Share what you know: Keep in mind that you are not responsible for communicating all of the information; you are there to jumpstart a conversation. Stick to main points to help your family cognitively and emotionally grasp the information. Let your family know that there are genetic counselors who can answer their personal questions and help them make decisions. Offer to go to a genetic counseling appointment with your family member, or if your family is far away, offer to coordinate a phone conference with them. You may want to consider bringing resources for your family to look through following the discussion, or suggest that they speak with a Rabbi, social worker, or other community leader to aid in decision-making.

Assess what your family knows: Talk to your family about their own experiences and knowledge. Let them guide the discussion. They may be familiar with genetics and the impact of family history or this information may come as a surprise. Use this to guide your discussion. After sharing basic information, what are they most concerned about? Let your family know you will answer their questions to the best of your ability and that some questions should be answered by a genetic counselor.

Gauge how family members respond: Is your family member confused? Angry? Upset? Relieved? Addressing their emotional response can be a helpful tool in your conversation. Remember that this information can be hard to hear. Family members may struggle to understand the information or to cope with it. If the conversation becomes too challenging, offer to restart it at a later time.

Continue the conversation: The communication process can bring families closer together because of a shared experience. Use this process to bring your family together, keep the lines of communication open, and continue the conversation over time.