Q and A: What is the benefit of visiting a genetic counselor?

14 June 2022, by Cynthia Weiss

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DEAR MAYO CLINIC: My grandmother and mother, as well as an aunt and a cousin, have had breast cancer. Another cousin was diagnosed with colon cancer recently. It has been suggested that I undergo genetic counseling to determine my cancer risk. As a young man, is genetic testing necessary for me? What benefit would I gain from visiting a genetic counselor?

ANSWER: Although it can be daunting to have a loved one diagnosed with cancer, having a family history does not mean that you will automatically get cancer. This is one of the reasons why having a discussion with a genetic counselor can be valuable.

A genetic counselor is someone who reviews your personal health history and your family's health history to identify your personal risk for certain conditions. A genetic counselor can try to determine if there is a pattern or connection among family members' diagnoses and how that may affect you.

For instance, you mentioned that your grandmother, mom and a cousin have had breast cancer, but it's unclear if all of these women are on the same side of the family. If they are all related—for example they are all on the maternal side of your family—then that suggests more of a pattern that could potentially increase your risk, even as a man. Breast cancer affects men, too, though it occurs more infrequently.

People seem to be most aware of genetic counseling when it comes to breast cancer. This likely is due to the fact that the most common genes associated with increased breast cancer risk—BRCA1 and BRCA2—have received a lot of media attention over the years. In general, though, only about 5%-10% of breast cancers have a hereditary cause that can be identified. If a hereditary cause for breast cancer is discovered, this condition may increase the risk for other types of cancer, as well.

Other cancers that may have a hereditary connection include ovarian, colon, prostate, uterine and pancreatic cancers. Concerns for a hereditary cancer syndrome rise if people are diagnosed at younger ages, have a personal history of more than one cancer, or have multiple family members with the same or associated cancers. This information may be useful for you if you decide to have children. You'll be able to determine the likelihood that you might pass along a gene and increase the risk to your offspring for certain cancers.

Meeting with a genetic counselor doesn't immediately mean that you need genetic testing. Rather, the goal of the appointment is to have a discussion that can guide you toward making an informed decision regarding genetic testing. Discussing the potential risks and limitations of genetic testing are just as important as reviewing

potential benefits of testing.

Another benefit of meeting with a genetic counselor is to learn more about your family risk for certain conditions, which could be valuable in the future. For instance, understanding your risk for cancer is important, but learning about certain hereditary heart and neurologic conditions, as well as more rare genetic conditions like cystic fibrosis, might help with family planning down the road.

Sometimes reviewing all of this information together allows things to be put in a new context. For some families, it illustrates a clear pattern of increased risk for certain conditions. In other cases, though, it may lower your concern.

I recall a young woman who came to see me to discuss her significant family history of cancer. But as we began charting her family tree, we realized that only a few relatives had developed skin cancer, and they worked outdoors on a farm or in construction. In reality, her cancer risk was minimal given her lifestyle.

Although it can be challenging to learn about the details of your family's health tree, especially if prior generations didn't share as much or document health concerns, it is important to talk with your family prior to meeting with a genetic counselor if you can.

Family history should be gathered for three or four generations on both sides, and include parents, grandparents, aunts, uncles, cousins and children.

Helpful information to gather includes:

- Major medical conditions and the age they started.
- Cause and age of death.
- Birth defects.
- Family's ethnic background, as some conditions can be more prevalent in certain ethnicities. For instance, if someone is of Ashkenazi Jewish descent, the risk for hereditary breast and ovarian cancer syndrome is greater than in the general population.

A good resource to help you get started is a free online tool called My Family Health Portrait. This tool is available through the surgeon general's office. It allows you to collect the information and create a family pedigree that can be printed and shared with health care professionals and your family.

As you discuss your family history, don't forget to talk about conditions that may not have a strictly genetic cause but may have a genetic link. Although there are conditions such as diabetes where a genetic test is not available, it's important to document the patterns in your family and share them with your primary care provider.