Q&A: Family health history information

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My grandmother died of breast cancer at 70. My first cousin was recently diagnosed at 35. And another cousin also had breast cancer a few years ago. A friend suggested that I undergo genetic counseling to determine my risk. Is that necessary? Can a genetic counselor tell me anything else about my risk for other diseases?

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 looks at your personal health history and your family's health history to identify your personal risk for certain conditions. One of the benefits of meeting with a genetic counselor is that he or she can try to determine if there is a pattern or connection between family members' diagnoses and how that may affect you.

For instance, you mentioned that your grandmother and several cousins have had breast cancer, but it's unclear if all of these women are actually 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 is more suggestive of a pattern that could potentially increase your risk.

People seem to be most aware of genetic counseling in the setting of 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.

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.

Also, genetic counselors and geneticists see patients for other health conditions, including certain heart and neurologic conditions, as well as

more rare genetic conditions, like cystic fibrosis.

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.

Understanding your family's health tree can be challenging, especially if prior generations didn't share much or document health concerns. You're encouraged to talk to your family prior to meeting with a genetic counselor if you can.

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 recently 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 risk for cancer was minimal given her lifestyle.

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, his or her risk for hereditary breast and ovarian cancer syndrome is greater than the general population.

One good resource to help you get started is a free online tool called My Family Health Portrait, which 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 providers 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 it with your primary health care provider.