What to Expect When Meeting With a Genetic Counselor

This section has been reviewed and approved by the Cancer.Net Editorial Board [1], March / 2012

Listen to the Cancer.Net Podcast: Meeting With a Genetic Counselor [2], adapted from this content.

Genetic counseling involves having a trained genetic counselor help you and your family understand your risk of an inherited medical condition (a condition passed from parent to child), such as a type of cancer, based on your personal and family medical history. The genetic counselor explains the available genetic tests; the cancer screening, prevention, and treatment options; and serves as an ongoing resource for support.

A genetic counselor's training and certification

A genetic counselor is a health professional with specialized training in medical genetics and counseling. Most genetic counselors have a Master's degree in genetic counseling, although some have degrees in related fields, such as nursing or social work. Genetic counselors are certified through the American Board of Genetic Counseling. They are often licensed by their state and like other health professionals, they must participate in continuing education to maintain their certification.

The role of a genetic counselor in your cancer care

Genetic counselors are trained to advise you about the following:

- Your risk of developing specific types of cancer, based on your family history
- The availability of genetic tests to give you more information about your risk of these types of cancer
- The limitations of the testing procedures and the accuracy of those tests
- The emotional, psychological, and social consequences of knowing the test results
- Cancer screening [3] and surveillance options
- Preventive measures
- Diagnostic and treatment options
- The confidentiality (privacy) of your genetic information

Preparing for an appointment with a genetic counselor

The value of your genetic counseling appointment increases with the amount of information you have about the history of cancer in your family. Helpful information that may be requested by the genetic counselor includes the following:

- Your medical records. This includes doctors' notes and pathology reports [4] (laboratory test results) from any biopsies, surgeries, or standard screening examinations (such as colonoscopies).
- A list of extended family members that includes each person's current age or age at the time of death and cause of death. This list should include parents, siblings, children, aunts, uncles, nieces, nephews, grandparents, and cousins.
- Information regarding the specific types of cancer that have been diagnosed in the family. This should include the age at which family members were diagnosed with cancer. Pathology reports are often helpful.

Although having as much of this information available is most helpful, it is not necessary most of the time. You should not avoid genetic counseling just because you do not know a lot about your family history.

Meanwhile, consider taking someone with you to your appointment. This may or may not be a family member, depending on your preference. The genetic counselor will cover a large amount of information, and another person can help you listen and think of questions. If you choose to bring a family member, that person may also be able to provide information about your family history.

What to expect during the appointment

The following topics will be covered during your appointment with a genetic counselor:

- Your personal medical history and cancer screening history.
- Your family history of cancer. The counselor will draw your family tree and include at least three generations, documenting which family members have had cancer, what type of cancer they had, and their age at diagnosis.
- The possibility of a hereditary cancer risk (cancer risk passed from parent to child) in your family. Depending on your family history, your

counselor may be able to use computerized risk assessment tools to help estimate your risk.
- The benefits and limitations of genetic testing for your family
- A strategy for genetic testing that best meets your needs
- Current laws regarding the privacy of genetic information

What to expect after the appointment

Your genetic counselor will write a summary of your appointment. Typically, a copy of this report will go to you and to the doctor who referred you to the genetic counselor. Your genetic counselor may also provide you with written information relevant to your family history. In some cases, you or other family members may qualify for research or screening studies, and your genetic counselor can provide you with information about those studies and help you make the necessary arrangements.

If you decide to pursue genetic testing, your counselor will help you coordinate the details, including working with the testing laboratory to determine if test costs are covered by your insurance. When the test results are available, your counselor can review them with you and help you understand them.

In the long term, your genetic counselor will continue to be a resource for you and your family. It is important to call your counselor if you have any questions or if changes occur in the cancer history of your family.

Finding a genetic counselor

To find a genetic counselor in your area, ask your doctor for references or search the National Society of Genetic Counselors [5] and National Cancer Institute [6] databases.

More Information

Genetic Testing [7]

Sharing Genetic Test Results With Your Family [8]

Understanding Cancer Risk [9]

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Links:
[1] http://www.cancer.net/about-us
[2] http://www.cancer.net/sites/cancer.net/files/meeting_a_genetic_counselor.mp3
[3] http://www.cancer.net/node/24972
[4] http://www.cancer.net/node/24715
[5] http://www.nsgc.org/FindaGeneticCounselor/tabid/64/Default.aspx
[6] http://cancer.gov/cancertopics/genetics/directory
[7] http://www.cancer.net/node/24895
[8] http://www.cancer.net/node/24906
[9] http://www.cancer.net/node/25007