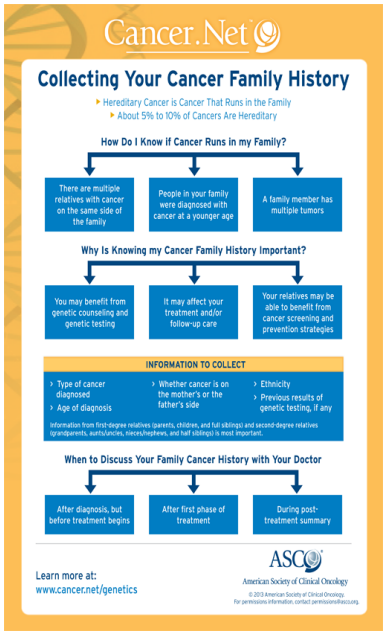
Collecting Your Family Cancer History [1]

This section has been reviewed and approved by the Cancer.Net Editorial Board [2], 01/2014

Larger Image [3]



[3]When you are diagnosed with cancer, it is important to share your family history with your doctor. This is often the first step in finding out whether your cancer is hereditary, meaning you were born with a genetic change that made you more likely to develop cancer. Knowing that the cancer is hereditary enables your doctor to personalize your treatment and follow-up care, as well as develop a screening and prevention plan that addresses any risk for other cancers. As important, your at-risk family members can talk with their doctors about ways to protect their own health.

Genetic testing

Approximately 5% to 10% of all cancers are considered hereditary. Clues to hereditary cancer include multiple relatives with cancer on the same side of the family, cancers diagnosed at an early age, and a single person with multiple tumors (especially in the same organ).

Hereditary cancer is found through genetic testing, which is the analysis of genes, chromosomes, or proteins to help predict the risk of disease, identify carriers of a disease (individuals who do not have the disease but have a copy of the disease gene), diagnose disease, or determine the likely course of a disease. It is done by testing a

person?s blood or a tissue sample that contains genetic material, such as the cells inside a person?s cheek. More than 900 genetic tests are available for many different diseases, including breast, ovarian, colon, thyroid, and other cancers. Learn more about genetic testing [4].

What your family cancer history can show

Information from your cancer family history can help doctor to determine whether:

- You or others in your family may benefit from genetic counseling [5] (counseling that explains the risks of an inherited cancer and the benefits, risks and limitations of genetic testing) and/or genetic testing
- You require more intensive follow up than patients with non-hereditary cancer, even if you do not need genetic testing

Information to collect

Your doctor will want information on the cancer history of your first-degree relatives (parents, children, and full siblings) and second-degree relatives (grandparents, aunts/uncles, nieces/nephews, grandchildren, and half siblings). For each relative who has had cancer, collect as much of this information as possible:

- Type of cancer(s)
- Age diagnosed with each cancer
- Lineage, meaning is it maternal (on the mother?s side) or paternal (on the father?s side)
- Ethnicity (some ethnicities, such as the Ashkenazi Jewish population, are at greater risk for certain cancers)
- Results of any previous cancer-related genetic testing

Keep in mind that it might be difficult for some of your family members to discuss their health with you. You may want to send your questions ahead of time and emphasize that even a little information is helpful. Try to find a time to talk that is free of distractions.

When to share your family cancer history with your doctor

Provide your cancer family history to your doctor soon after your diagnosis and before you begin treatment (if possible). It is also important to let your doctor know of any new information you gather or changes to your family history. Sometimes, medical advances may change how your doctor evaluates your history. Good opportunities to review your cancer family history are after your first phase of treatment, during your post-treatment summary, and as part of your post-treatment survivorship appointment.

How to collect and share your cancer family history

One way to gather information is to use ASCO?s Cancer Family History [6] questionnaire. After you complete the form to the best of your ability, bring it with you to your next doctor?s appointment and ask to discuss it. You should also send the form to your close relatives so they have the information to share with their doctors. Although, be aware that a few relatives may not want or value this information in this same way you do.

Questions to ask your doctor

If, after reviewing your cancer family history, your doctor suspects that you may have a hereditary cancer, it is important to understand what this means and what next steps are available. Consider asking the following questions of your health care team:

- Does my family history put me at risk for other cancers?
- Do you advise that I receive genetic counseling and/or genetic testing?
- Can you recommend a genetic counselor or a way to find one?
- What is the purpose of genetic testing?
- Will information from genetic testing change your treatment plan for me?
- Is genetic counseling and testing covered by my insurance plan?
- Is my genetic information protected?
- Which of my family members are at risk?
- Does someone who inherits a genetic mutation always develop cancer?
- What information do I need to share with family members?
- Do you have any suggestions for helping me communicate this information?

More Information

What to Expect When Meeting with a Genetic Counselor [5]

Sharing Genetic Test Results with Your Family [7]

Hereditary Cancer-Related Syndromes [8]

Additional Resources

National Cancer Institute (NCI): Genetic Testing for Hereditary Cancer Syndromes [9]

Centers for Disease Control and Prevention: Family Health History [10]

Genetic Alliance: Family Health History [11]

U.S. Department of Health and Human Services: Surgeon General?s Family Health History Initiative [12]

Locating Cancer Genetics Specialists

National Society of Genetic Counselors: Find a Genetic Counselor [13]

NCI: Cancer Genetics Services Directory [14]

American College of Medical Genetics: Clinical Services Search Engine [15]

American Board of Medical Genetics: Search for a Certified Geneticist [16]

American Board of Genetic Counseling: Find a Counselor [17]

Links:
[1] http://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/collecting-your-family-cancer-history
[2] http://www.cancer.net/about-us
[3] http://www.cancer.net/sites/cancer.net/files/cancer_family_history_infographic.pdf
[4] http://www.cancer.net/all-about-cancer/genetics/genetic-testing
[5] http://www.cancer.net/all-about-cancer/genetics/what-expect-when-meeting-genetic-counselor
[6] http://www.cancer.net/sites/cancer.net/files/cancer_family_history_questionnaire.pdf
[7] http://www.cancer.net/all-about-cancer/genetics/sharing-genetic-test-results-your-family
[8] http://www.cancer.net/all-about-cancer/genetics/hereditary-cancer-related-syndromes

[9] http://www.cancer.gov/cancertopics/factsheet/Risk/genetic-testing
[10] http://www.cdc.gov/genomics/famhistory/
[11] http://www.geneticalliance.org/fhh
[12] http://www.hhs.gov/familyhistory/
[13] http://nsgc.org/p/cm/ld/fid=164
[14] http://www.cancer.gov/cancertopics/genetics/directory
[15] http://www.acmg.net/GIS/Default.aspx
[16] http://www.abmg.org/pages/searchmem.shtml
[17] https://abgcmember.goamp.com/Net/ABGCWcm/Find_Counselor/ABGCWcm/PublicDir.aspx?hkey=0ad511c0-d9e9-4714-bd4b-0d73a59ee175