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# To Know or Not To Know

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Though genetic testing requires little more than a simple blood draw, learning about one's genetic status may open a Pandora's box of personal and familial issues. Grappling with the sometimes unexpected implications of such testing can challenge even the closest of families. For this and other reasons, the American Society of Clinical Oncology recommends that testing be done only within the context of genetic counseling.

Working with genetics professionals, individuals, and families explore the possible consequences of genetic testing and develop realistic expectations of what may or may not be learned in the process. Appropriate candidates for genetic testing include individuals with one or more of the following: early-onset cancers (usually under age 50 for adult onset syndromes), more than one cancer diagnosis, a strong family history of cancer or the presence of rare cancers, such as male breast cancer and fallopian tube cancer.

In the ideal case, testing provides information that either confirms high-risk status or rules out the presence of a genetic alteration found in other family members. For those who test positive, increased screening may detect cancer at an early stage, allowing patients to avoid aggressive treatments like chemotherapy. In other cases, cancer may be prevented altogether using prophylactic (preventive) surgeries. Because gene alterations often predispose individuals to many types of cancer, identifying genetic status early on can drastically affect long-term outcomes.

As helpful as genetic testing may be, it occasionally raises more questions than it answers. Results in some cases may be uninformative or ambiguous, as in families with a strong history of cancer who receive "negative" test results. These families may actually carry an alteration in a gene yet to be discovered or one that cannot be detected using current technologies. In other cases testing may reveal a genetic variant of unknown significance, leaving cancer specialists unable to interpret results or accurately assess cancer risk. Such results make it harder to determine the best course of action and do little to alleviate worry.

Genetic testing is now available for dozens of hereditary cancer syndromes, most of which are caused by alterations in genes that suppress tumor growth. To date the most commonly requested test is for BRCA1 and BRCA2. Alterations in these two genes predispose individuals to breast, ovarian and other cancers, and are found more frequently in families of Ashkenazi Jewish descent.

Among female carriers, BRCA alterations confer a lifetime breast cancer risk of up to 85 percent and an ovarian cancer risk of up to 50 percent. Male carriers also

have increased risk for breast, prostate and other cancers. Other genetic tests commonly requested include analyses for two colon cancer syndromes: hereditary nonpolyposis colon cancer (HNPCC) and familial adenomatous polyposis (FAP). Both syndromes are associated with a significantly increased risk for colon cancer (80 percent and virtually 100 percent, respectively), as well as other cancers.

The cost of genetic testing ranges from a few hundred to several thousand dollars, depending upon the number of genes tested and the number of sites analyzed within a given gene. Because three recurrent mutations account for the vast majority of BRCA-related cancers in Ashkenazi Jews, testing is abbreviated and much less expensive than that for the general population (\$460 as opposed to \$3,120). For appropriate candidates, insurance often covers most or all of the cost of genetic testing.

To find a genetic counselor in your area, visit the National Cancer Institute's website at [www.cancer.gov/search/genetics\\_services](http://www.cancer.gov/search/genetics_services).