

Putting the Pieces Together to Assess Your Ovarian Cancer Risk

More than a decade ago, scientists discovered that defects in two specific genes (BRCA1 and BRCA2) were linked to breast cancer. The finding confirmed that breast cancer risk could be passed from one generation to the next through those genes. But many women are not aware of another danger hiding in the shadows of the breast cancer genes: ovarian cancer.

Unlike breast cancer or cervical cancer, ovarian cancer has no reliable screening test, and symptoms are vague or nonexistent. For these reasons, ovarian cancer typically is diagnosed at an advanced stage, when the disease is difficult to cure. But there are clues that could alert a woman to her potential risk.

“Some families appear to be especially susceptible to cancer,” says Tara Namey, certified genetic counselor in Lehigh Valley Hospital and Health Network’s cancer risk assessment program. “If you have a strong family history of cancer, talking to a genetic counselor is the first step in assessing your risk—and you may or may not need to follow that with genetic testing.”

Consider genetic counseling if you have several family members who’ve had cancer of any kind, especially if they are all on one side (mother’s or father’s) of the family. Also consider counseling if you have a personal or family history of any of these situations:

- **Breast cancer diagnosed at age 45 or younger**
- **Two or more close relatives with breast and/or ovarian cancer, especially if it occurred before menopause;**
- **Breast cancer in more than one generation;**
- **Breast cancer in both breasts;**
- **Both breast and ovarian cancer in the same woman;**
- **More than one family member with ovarian cancer;**
- **A man in your family who had breast cancer;**
- **Ashkenazi (Eastern and Central European) Jewish heritage, and ovarian cancer at any age or breast cancer before age 60;**
- **A relative with a known mutation in BRCA1 or BRCA2;**
- **A family history of hereditary non-polyposis colorectal cancer syndrome.**



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The first step in genetic counseling involves completing a four-generation family “pedigree”—you’ll be asked the age, age at cancer diagnosis or age of death for every family member with cancer. (There will be plenty of time to complete this before meeting with the genetic counselor.)

When you meet with the counselor, you will discuss:

- **Your risk, based on your family and personal history;**
- **Risk-reduction strategies,**
- **The screenings you need, including breast self-exams, mammography, pelvic exams and possibly MRI;**
- **Genetic testing to determine whether you carry the BRCA1 or BRCA2 gene.**

Some women choose not to be tested, Namey says, because their risk is low or because knowing they have the gene would make them too anxious. But having the gene does not mean you will get breast or ovarian cancer. (Most cancers occur in women with no family history.) It simply alerts you to be especially vigilant.

If you choose to be tested, your DNA will be analyzed through a blood sample. The type of testing required depends on how much you know about your heritage. If someone in your family has tested positive for a defective gene, researchers only look for that specific mutation. If nothing is known about specific defects, the entire DNA sequence is examined. Results take about four weeks.

Cost can range from a few hundred dollars (for testing for one mutation) to about \$3,000 (for full gene sequencing). The testing often is covered by insurance. Some people are concerned about potential discrimination by insurers and employers, but Namey says this is unlikely because of protections that have been placed on confidential medical information.

If it turns out that you have a defective gene, knowing your risks can empower you to take active steps to prevent cancer. It also can help with decision-making for yourself and other family members, Namey says. While having the gene does not necessarily mean you will get cancer, it does raise your risk significantly:



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- Your risk for ovarian cancer is 27-44 percent, compared to 1.7 percent in the general population;
- Your risk for breast cancer is 56-85 percent, compared with 13.2 percent in the general population;
- You have a 50 percent chance of passing the gene on to your children.

How will you use this information? Some women who have the gene choose preventive surgery to reduce their risk, although it's still possible to develop cancer even when organs have been removed.

- Removing healthy ovaries and fallopian tubes can reduce ovarian cancer risk by 96 percent and breast cancer risk by 47 percent;
- Removing both healthy breasts can reduce breast cancer risk by 90 percent.

If you choose not to undergo preventive surgery, your genetic counselor will recommend an aggressive screening and risk-reduction program that may include:

- monthly self-exams;
- annual mammograms beginning at age 25 or 30;
- annual breast MRI;
- clinical exams by a doctor twice a year;
- education about subtle signs and symptoms of ovarian cancer;
- trans vaginal ultrasounds twice a year
- oral contraceptives, which may reduce ovarian cancer risk;
- preventive chemotherapy such as tamoxifen.



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If you develop breast cancer, knowing you have the gene can influence treatment decisions. For example, you may consider a mastectomy (removal of both breasts) more than a lumpectomy (removal of the lump) because of higher risks for developing a second breast cancer.

Sharing this knowledge with other family members can help them take steps to reduce their risk as well.

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Genetic testing also may reveal that you don't have the gene, which could lower your risk and your anxiety. You should still follow recommendations for a healthy lifestyle and cancer screenings.

"This can be very complex and confusing information," Namey says. "We will help you understand the full picture, what it means and what to do about it. While these are highly personal decisions that need to be carefully considered with your family, you don't have to go through it alone."

To schedule an appointment with a counselor in the cancer risk assessment program, call 610-402-CARE.



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