



Understanding Your Risk of Ovarian Cancer

A WOMAN'S GUIDE

FOUNDATION FOR
WOMEN'S CANCER



Gynecologic Cancer
Awareness • Research • Education

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Ovarian Cancer

Ovarian cancer will affect 1 in 70 women in the United States over their lifetime and is the deadliest gynecologic cancer. While once thought to be a “silent” killer, ovarian cancer frequently has identifiable symptoms that may lead to detection at an earlier and more treatable stage, which is associated with a greatly improved prognosis. Additionally, while **ALL WOMEN ARE AT RISK FOR OVARIAN CANCER**, some women have a personal or family history that may further substantially increase their risk.

This brochure will describe:

- Symptoms of ovarian cancer
- Your personal level of risk
- Screening and prevention strategies that can reduce the risk

Please read this brochure and talk to your doctor about your individual risk of developing ovarian cancer, and what you and the women in your family can do to reduce this risk.

Does Ovarian Cancer Have Symptoms?

Recent studies have shown that the following symptoms are much more likely to occur in women with ovarian cancer than women in the general population:

- Bloating
- Pelvic or abdominal pain
- Difficulty eating or feeling full quickly
- Urinary symptoms (urgency or frequency)

Women with ovarian cancer report that these symptoms are persistent and represent a change from normal for their bodies. The frequency and/or number of symptoms are a key factor in the diagnosis of ovarian cancer. Women who have any of the above symptoms, almost daily, for more than 2-3 weeks should see their doctor, preferably a gynecologist. Studies have shown that even early stage ovarian cancer can produce these symptoms. Prompt medical evaluation of these symptoms may lead to detection of ovarian cancer at the earliest possible stage. And early stage detection is associated with an improved outcome.

Several other symptoms have also been commonly reported by women with ovarian cancer. These symptoms include:

- Fatigue
- Indigestion
- Back pain
- Pain with intercourse
- Constipation
- Menstrual irregularities

However, these other symptoms alone are not as useful in identifying ovarian cancer. That's because they are also found in equal frequency in women in the general population who do not have ovarian cancer.

Evaluation of Symptoms

It is important to understand that the symptoms associated with ovarian cancer are common. They are also often due to other causes. All women can have these symptoms from time to time, but that does not mean that they have ovarian cancer. However, if you have bloating, pelvic or abdominal pain, difficulty eating or feeling full quickly, or urinary urgency or frequency that is new, occurs almost daily, and lasts for more than 2–3 weeks, seek prompt gynecologic evaluation. This could be a sign of ovarian cancer.

This evaluation should include both a pelvic and a rectovaginal exam.

If the symptoms do not resolve, or the exam is abnormal, you may need to undergo a transvaginal ultrasound to evaluate the ovaries or a blood test for the protein CA 125. These tests are further described in the next section. If an abnormality in either of these tests is found, additional studies may need to be performed.

TESTS USED TO EVALUATE THE OVARIES

Transvaginal ultrasound: This is a test in which a special wand is inserted into the vagina. The wand provides pictures that can show if there are tumors in and around the ovaries. It is most often used to evaluate pelvic symptoms. For some women at very increased risk of ovarian cancer, it may be useful as part of an ovarian cancer risk-reduction program. Because this test is frequently abnormal even when there is no cancer or other medical concern, it is not recommended as a routine ovarian cancer screening tool for women at average or slightly increased risk in the absence of symptoms.

CA 125 blood test: This test measures the level of a protein released by some ovarian cancer cells into the bloodstream. For women at very increased risk of ovarian cancer, regular measurement of CA 125 is sometimes used to help screen for ovarian cancer.

Because the CA 125 protein is also frequently released by other normal cells, CA 125 testing is not recommended for ovarian cancer screening for women at average or slightly increased risk who do not have symptoms.

What Is My Personal Risk of Ovarian Cancer?

As mentioned earlier, ALL WOMEN ARE AT RISK OF OVARIAN CANCER, with 1 in 70 women developing this disease over their lifetime. Some women, however, have personal or familial factors which further increase this risk. Using information about whether these other factors are present allows you and your doctor to determine the ovarian cancer risk-reduction approach best suited for your level of risk. Make sure to read all four risk levels to determine your personal risk.

AVERAGE RISK

[Lifetime risk of approximately 1 in 70]

- You don't have any family history of breast or ovarian cancer.
- You have never had difficulty getting pregnant.
- You have never taken hormone replacement.

Ovarian cancer screening recommendations for women at average risk:

- Have a gynecologic exam once a year.
- Be aware of the symptoms of ovarian cancer and contact your doctor if these are new, occur almost daily and are present for more than 2-3 weeks.

Ovarian cancer prevention options for women at average risk:

- Consider using birth control pills if you are in the reproductive age group. (This option is further discussed in the section on ovarian cancer prevention.)

SLIGHTLY INCREASED RISK

[Lifetime risk of up to 1 in 20]

- Do you have a history of infertility (difficulty getting pregnant)?
- Have you used medicines to help you get pregnant?
- Do you have a history of endometriosis?
- Have you taken hormone replacement therapy to help manage menopausal symptoms?
- Have you had breast cancer after age 40?

Ovarian cancer screening recommendations for women at slightly increased risk:

- Have a gynecologic exam once a year.
- Be aware of the symptoms of ovarian cancer and contact your doctor if these are new, occur almost daily and are present for more than 2–3 weeks.

Ovarian cancer prevention options for women at slightly increased risk:

- Consider using birth control pills if you are in the reproductive age group and have not had breast cancer. (This option is further discussed in the section on ovarian cancer prevention.)

MODERATELY INCREASED RISK

[Lifetime risk of up to 1 in 10]

- Has your mother, sister or daughter had ovarian cancer?
- Have you had breast cancer before age 40?
- Have you had breast cancer before age 50, and have one or more close blood relatives had breast or ovarian cancer at any age?
- Have two or more close blood relatives had breast cancer before the age of 50 or ovarian cancer at any age?

- Are you of Eastern European (Ashkenazi) Jewish heritage? If yes, then:
 - Have you or a close blood relative had breast cancer before age 50?
 - Has a close blood relative had ovarian cancer at any age?
- Have you or a close blood relative had uterine cancer prior to age 50?
- Have you or a close blood relative had colon cancer prior to age 50?

Recommendations for women at moderately increased risk:

- **Genetic counseling is highly recommended** to better clarify your risk, and to help determine the best screening and prevention options for you. (This option is further discussed in the section on genetic counseling and genetic testing.)

VERY INCREASED RISK

[Lifetime risk of up to 1 in 2]

- Has genetic testing shown that you have a change in the *BRCA1* or *BRCA2* genes which is associated with a very increased risk of breast and ovarian cancer?
- Has genetic testing shown that you have a change in the *MLH1*, *MSH2* or *MSH6* genes which is associated with a very increased risk of colon, uterine, ovarian and kidney cancer?

Screening and prevention recommendations for women with BRCA1 or BRCA2 mutations:

- Have a gynecologic exam 1–2 times per year.
- Be aware of the symptoms of ovarian cancer and contact your doctor if these are new, occur almost daily and are present for more than 2–3 weeks.
- Have both a transvaginal ultrasound and the CA 125 blood test two times per year starting at age 30–35 until the ovaries and fallopian tubes are removed preventively.

- Have breast cancer screening with annual mammogram and breast MRI starting at age 25–30.
- Undergo preventive removal of the ovaries and fallopian tubes after childbearing is done. (This option is further discussed in the section on ovarian cancer prevention.)

Screening and prevention recommendations for women with MLH1, MSH2 or MSH6 mutations:

- Have a gynecologic exam 1–2 times per year.
- Be aware of the symptoms of ovarian cancer and contact your doctor if these are new, occur almost daily and are present for more than 2–3 weeks.
- Report any abnormal vaginal bleeding to your doctor.
- Have both a transvaginal ultrasound and the CA 125 blood test 1 to 2 times per year starting at age 30–35 until the uterus, ovaries and fallopian tubes are removed preventively.
- Have a biopsy of the uterine lining once a year to detect uterine cancer or pre-cancer.
- Have a colon cancer screening with colonoscopy every 1–2 years, starting at age 20–25.
- Undergo preventive removal of the uterus, ovaries and fallopian tubes after childbearing is done. (This option is further discussed in the section on ovarian cancer prevention.)

What Is Genetic Counseling and Genetic Testing?

Genetic Counseling is a process during which a genetic counselor or other appropriate medical professional will ask a series of questions about you and your family’s cancer history as well as your heritage. This information will be used to assist the genetic counselor in determining if you may be at increased risk of ovarian and related cancers.

Undergoing genetic counseling can be helpful if you have a personal or family history of cancer, even if no genetic testing is pursued.

Genetic Testing is a process in which a blood test may help to determine if you or your family members are at very high risk of ovarian and related cancers. The blood test looks to see if you are carrying a gene change passed down to you by one of your parents that causes a very high risk of cancer. Everyone carries thousands of genes. However, some people carry gene changes that have a high risk of causing cancer. The different genes that can carry changes that cause a very high risk of ovarian cancer are:

- **BRCA1 or BRCA2:** Women who carry a change in one of these genes have up to a 60% lifetime risk of developing ovarian cancer and up to an 85% lifetime risk of developing breast cancer. These cancers can also occur at ages much earlier than seen in the general population with some breast cancers being seen as early as the mid-20's.
- **MLH1, MSH2 or MSH6:** Women who carry a change in one of these genes have up to a 12% lifetime risk of developing ovarian cancer. Women with changes in these genes also have up to a 60% lifetime risk of both uterine and colon cancer. Similar to BRCA1 and BRCA2, changes in these genes can cause very early onset cancers, with some of the cancers occurring as early as age 25.

Importantly, changes in these genes can be inherited from either a mother or a father. While most of the cancers associated with changes in these genes only occur in women, men with changes in these genes can also be at increased risk of developing certain cancers. For this reason, men whose family history meets any of the increased risk criteria outlined previously are encouraged to talk with their doctors.

What Can I do to Prevent Ovarian Cancer?

There are currently two options to prevent ovarian cancer. Each option is an individual choice that should to be discussed with your doctor.

Medications: Birth control pills (oral contraceptives) have been shown to reduce the risk of ovarian cancer by 30–60%. The longer someone uses oral contraceptives, the greater the protection. At least 3–5 years of use is recommended for ovarian cancer protection. This protection also continues for many years after the pills were last taken.

However, oral contraceptives have been linked to breast cancer and may be associated with other health risks. You should only use oral contraceptives after discussing the risks and benefits with your doctor.

Preventive Surgery: Removing the ovaries and fallopian tubes is the most effective option to prevent ovarian cancer. This surgery can reduce the risk of ovarian and related cancers by 85–90%. For pre-menopausal women, removal of the ovaries and fallopian tubes can also reduce the risk of breast cancer by 40–70%.

Preventive surgery is generally recommended only if you have undergone genetic testing and been shown to have a gene change associated with a very increased risk of ovarian cancer. In rare cases, surgery may also be recommended after negative genetic testing if you have a very strong family history of ovarian and related cancers. Additionally, you should have completed your child-bearing. Most women consider having this procedure between the ages of 35 and 40. This is, however, a very important and personal decision.

Make sure to discuss the pros and cons of surgery with your doctor. Removal of the ovaries causes menopause. Menopause symptoms can include hot

flashes, night sweats, vaginal dryness, mood changes and sleep disturbances. Premature menopause may also increase the risk of other important health conditions, such as osteoporosis and cardiovascular disease.

If you suspect or have been diagnosed with ovarian cancer, seek care from a gynecologic oncologist, a specialist trained in treating reproductive cancers like ovarian cancer. To find a nearby gynecologic oncologist, visit the Foundation for Women's Cancer website "find a gynecologic oncologist" section (f4wc.org).

LEARN MORE ABOUT OVARIAN CANCER:

Foundation for Women's Cancer

1.800.444.4441

f4wc.org

The National Cancer Institute

1.800.4.CANCER

cancer.gov/cancertopics/types/ovarian/

LEARN MORE ABOUT GENETIC COUNSELING AND TESTING:

Foundation for Women's Cancer

1.800.444.4441

f4wc.org

The National Cancer Institute

1.800.4.CANCER

cancer.gov/cancertopics/Genetic-Testing-for-Breast-and-Ovarian-Cancer-Risk

The information in this brochure is designed to aid women in making decisions about appropriate gynecologic care. This brochure does not substitute for evaluations with qualified medical professionals familiar with your individual circumstances. This brochure should also not be construed as dictating an exclusive course of treatment or procedure. Variations in practice may be warranted based on the needs of the individual women, resources, and limitations unique to the institution or type of practice.

FOUNDATION FOR WOMEN'S CANCER

 Gynecologic Cancer
Awareness • Research • Education

The Foundation for Women's Cancer is a 501(c)(3) not for profit organization dedicated to funding research and training, and ensuring education and public awareness of gynecologic cancer prevention, early detection and optimal treatment.



Project Hope for Ovarian Cancer Research and Education is a not-for-profit organization founded in memory of Hope Perry Goldstein. Its mission is to decrease the incidence of and mortality from ovarian cancer by:

- (1) educating women to better understand their risk;
- (2) affording increased survival through early detection and development of improved therapies; and
- (3) preventing the illness through awareness of screening and risk-reduction alternatives.