



What You Need to Know About Ovarian Cancer

About Us

The Rhode Island Ovarian Cancer Alliance (RIOCA) was formed in honor and memory of Jessica Morris. Jessica was diagnosed with Stage IIIC Ovarian Cancer just two weeks after her 18th birthday in October 2005. She underwent a full hysterectomy followed by several rounds of chemotherapy. It was at this point Jessica made it her mission to educate and raise awareness about Ovarian Cancer. Within a month of her surgery, she was back at Lincoln High School, educating her former classmates about Ovarian Cancer Symptoms and Warning Signs.

Several months after Jessica completed her chemotherapy, her cancer returned. The next couple of years Jessica continued her struggle going through additional surgeries and treatments. On August 29, 2008, surrounded by family and friends, Jessica lost her courageous battle.

When Jessica was first diagnosed it became her mission to educate and raise awareness about this horrific disease. We partnered with a national organization back in 2007 to bring education and awareness to the state of Rhode Island since there was no local Ovarian Cancer Organization.

In December 2015, we separated from the national organization and formed the Rhode Island Ovarian Cancer Alliance. Our mission is to promote awareness and education of the signs, symptoms, and risk factors of Ovarian Cancer, while providing support to survivors and their families. Our grass roots effort is led by a range of inspired and passionate stakeholders.

RIOCA offers a variety of special events, including an annual 5K Walk each September in Providence, Rhode Island to raise awareness, celebrate survivors and remember those lost to the disease.

What is Ovarian Cancer?

Ovarian Cancer is a disease in which malignant (cancerous) cells grow in one or both of the ovaries, which are part of a woman's reproductive system. An ovary is one of two almond-sized female reproductive organs located on either side of the uterus. The ovaries produce eggs (ova), as well as the female hormones, estrogen and progesterone.

Malignant cells in the ovaries can spread to other parts of the body (metastasize) either directly to other organs in the pelvis and abdomen or through the bloodstream or lymph nodes to other parts of the body.

All women are at risk for this disease, with 1 in 75 developing Ovarian Cancer in her lifetime. Ovarian Cancer is the leading cause of death from all gynecologic cancers and the fifth leading cause of cancer-related deaths in women in the United States. The American Cancer Society estimates 22,440 women will be diagnosed this year with Ovarian Cancer and 14,080 will die from the disease. Ovarian Cancer can occur at any age, but is most common among older women, with half of cases diagnosed in women ages 63 or older.

What's the general outlook for those diagnosed with Ovarian Cancer?

One of the first questions a woman asks when she is diagnosed with Ovarian Cancer is, "What are my chances for survival?" Because each woman diagnosed with Ovarian Cancer has a different profile, it is impossible to give a definitive prognosis. When the disease is detected early and confined to the ovary in which it arose, the 5-year survival rate—the percentage of patients who live at least 5 years after the cancer is detected—is over 90 percent.

Unfortunately, with no early screening tool, such as the Pap Test for cervical cancer, only 20 percent of all cases are caught before the disease spreads. Most women are diagnosed at advanced stages (stage III or higher) and about 50 percent will live longer than 5 years after diagnosis.

Is the disease hereditary?

Medical professionals don't know exactly what causes Ovarian Cancer. The single biggest risk factor for Ovarian Cancer is heredity. Approximately 5 to 10 percent of women diagnosed have a family history of the disease in one or more first-degree relatives (grandmother, mother, aunt, sister, daughter from either side of the family). A family history of cancers of the breast, colon, uterus or rectum may also increase a woman's risk.

The most significant risk factor for Ovarian Cancer is inheriting a defect in breast cancer susceptibility (BRCA) genes. Normally these genes help to prevent cancer, but if a woman has developed a mutation in the BRCA1 or BRCA2 gene, her ovaries and breasts are more susceptible to the development of cancer. **Studies show that inheriting a defect in these genes increases the risk of Ovarian Cancer by 10 to 20 percent.** Women of Eastern Europe and Ashkenazi Jewish descent are at higher risk of carrying BRCA1 and BRCA2 mutations.

However, while BRCA1 and BRCA2 are the most well known genes for Ovarian Cancer, many other gene mutations are also associated with the disease. A strong family history of Colon and Uterine Cancer, as well as other Gastrointestinal cancers, for instance, may indicate the presence of an inherited syndrome called HNPCC or Lynch Syndrome. While HNPCC is associated with a greater risk of Colorectal Cancer, women with HNPCC have about a 12 percent lifetime risk of developing Ovarian Cancer. Further studies will allow researchers to confirm these results.





What are some risk factors linked to Ovarian Cancer?

While having one or more risk factors may increase a woman's likelihood of developing Ovarian Cancer, it doesn't necessarily mean she will develop it. Risk factors include:

- Genetic predisposition
- Close family members on either mother's or father's side have had Ovarian Cancer
- Have had Breast, Uterine, Colorectal (colon) Cancer or Endometriosis
- Are middle aged or older
- Have never been pregnant
- Early onset of menstruation (before 12), or having late menopause (after 50)
- Long term use of hormone replacement therapy
- Obesity

Is Genetic Testing Right for You? Many experts strongly recommend that genetic testing be seriously considered if the individual has a personal or family history of cancer. But there are many pros and cons to consider. For more information on genetic testing, see the National Cancer Institute's fact sheet about genetic testing for inherited cancer risk, [cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet](https://www.cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet)

Can Ovarian Cancer be prevented?

At present, there is no known way to prevent Ovarian Cancer. However, there are some things that appear to lower the risk of developing the disease. They are:

Oral Contraceptives: Having used birth control pills for 5 or more years has been shown to reduce Ovarian Cancer risk by 50 percent compared with women who never used the pill.

Pregnancy and Breastfeeding: Having one or more children, particularly if the first is born before age 26, and breastfeeding may decrease a woman's risk.

Tubal Ligation: This surgical procedure, known as "having your tubes tied," entails the cutting or blocking of the fallopian tubes to prevent pregnancy. The procedure reduces the relative risk of developing Ovarian Cancer. It may be appropriate for high-risk individuals and should be discussed with your physician.

Removal of the Ovaries and Fallopian Tubes: Women can greatly reduce the risk of Ovarian Cancer by removing their ovaries and fallopian tubes, a procedure known as prophylactic (preventative) bilateral salpingo-oophorectomy. However, this surgery is generally only recommended for those who after testing have shown a genetic mutation associated with a high risk of Ovarian Cancer. The operation does not lower the risk of the less common primary Peritoneal Cancer, which is similar to Ovarian Cancer in spread, presentation, and treatment. The decision to undergo such preventive surgery should only be made after careful consideration of the pros and cons. Talk with your doctor to determine your individual risks and options for surgery.

Hysterectomy: According to the American Cancer Society, a hysterectomy, or removal of the uterus while leaving the ovaries, may decrease the risk of Ovarian Cancer by 33 percent. A woman should not have a hysterectomy exclusively to avoid the risk of developing cancer. But if one is being performed for valid medical reasons, the patient is over age 40, has a family history of ovarian or breast cancer, she should also discuss concurrent removal of her ovaries and fallopian tubes with her doctor.

Detecting Ovarian Cancer: What are the symptoms?

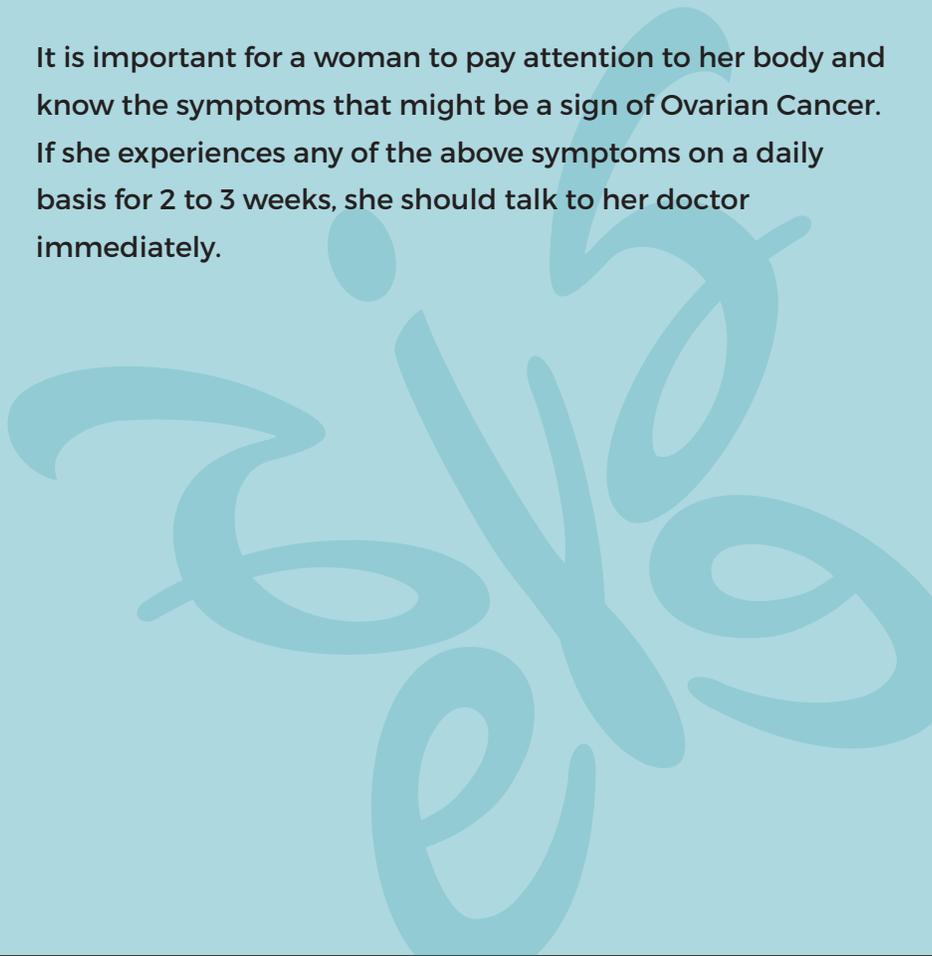
Early signs of Ovarian Cancer are often vague and any one of the disease symptoms can be confused with digestive or menstrual issues. But the following symptoms are more likely to occur in women with Ovarian Cancer than those women in the general population:

- Bloating, swelling of the stomach, sudden weight gain
- Difficulty eating; feeling full quickly
- Persistent pelvic or abdominal pain
- Needing to urinate urgently or more frequently

Other symptoms commonly reported:

- Upset stomach or heartburn
- Feeling very tired all the time
- Vaginal bleeding (especially if past menopause)
- Pain during intercourse
- Constipation
- Back pain
- Menstrual irregularities

It is important for a woman to pay attention to her body and know the symptoms that might be a sign of Ovarian Cancer. If she experiences any of the above symptoms on a daily basis for 2 to 3 weeks, she should talk to her doctor immediately.



What are some diagnostic tests that can detect Ovarian Cancer?

While new methods for early screening are being studied, there are currently no accurate screening tests for early detection of Ovarian Cancer. The Pap Test does not test for the disease; it screens for Cervical Cancer. These tests are available:

- **Annual gynecological** exam for women age 18 and above and an annual rectovaginal exam for women who are 35 or older. (The doctor inserts fingers in the vagina and rectum simultaneously to feel for an enlarged ovary or any other suspicious abnormality.)
- **Transvaginal sonogram.** This is an imaging method to examine a woman's reproductive organs and bladder and can reveal irregularities on the surface of the ovaries or within cysts that develop inside the ovaries. To administer the test, the doctor inserts a small probe inside the vagina.
- **Blood test, called CA-125,** to see if a protein (biomarker) produced by Ovarian Cancer Cells is elevated. This protein is elevated in some 80 percent of those with advanced Ovarian Cancer, and in 50 percent of those with early stage cancers. CA-125 is also used to detect closely related cancers, such as Fallopian Tube and Primary Peritoneal Cancer. However the test's usefulness is limited because noncancerous conditions can also raise CA-125 levels. The test is especially useful in monitoring women previously diagnosed and treated for Ovarian Cancer. Rising numbers over several tests suggest that a women is experiencing a disease recurrence.
- **OVA1 blood test.** This test has not yet been approved by the Food and Drug Administration for use as an Ovarian Cancer screening tool. However it calculates a score based on the measurement of five protein biomarkers in the blood that change when Ovarian Cancer is present. An abnormal result can prompt referral to a gynecologic oncologist.

What are the treatment options for Ovarian Cancer?

Women should always discuss treatment options with a physician because optimal treatment will depend on the stage of the disease, the woman's age, her general health and her desire to have children. The main treatment choices for Ovarian Cancer are:

- **Surgery:** During surgery, doctors try to remove as much of the visible cancer as possible (tumor debulking). Women who have the surgery performed by a gynecologic oncologist have seen outcomes including improved survival and longer disease-free periods than those whose surgeons were general gynecologists or other surgeons inexperienced in optimal debulking procedures.
- **Chemotherapy:** After surgery, a woman will usually be advised to undergo chemotherapy, in an effort to destroy any cancer cells both in and outside the ovaries.
- **Radiation:** Radiation therapy uses high-energy X-rays to shrink tumors and kill cancer cells. It is rarely used in the treatment of Ovarian Cancer.
- **Clinical trials:** Many people think clinical trials, research studies that follow a predefined set of procedures, are only for those whose treatments have failed. However a woman is eligible to participate in a clinical trial at any point: before, during or after treatment. Clinical trials can often provide the latest and most innovative medicine that experts think might help improve an individual's cancer outcome. To learn more, go to ClinicalTrials.gov.

Each year, **22,440** women are diagnosed with Ovarian Cancer. **14,080** women will die this year

Ovarian Cancer 101

- #1 Cause of Gynecologic Cancer
- 1 in 75 women will develop Ovarian Cancer in her lifetime
- Every 23 minutes a woman is diagnosed with Ovarian Cancer in the U.S.
- All women are at risk
- Symptoms, though vague, increase over time
- Early detection can lead to a better outcome
- A Pap Test does NOT detect Ovarian Cancer
- There is NO effective screening test for early detection

See a Gynecologic Oncologist

Repeated studies have shown that treatment performed by a gynecologic oncologist significantly improves a woman's chance of survival and decreases rates of recurrence. Gynecologic oncologists are not only skilled surgeons, but they have extensive and specialized training in cancers of the reproductive system. Some studies show survival rates as much as 50 percent greater, compared to surgeries performed by surgeons less experienced in Ovarian Cancer treatment techniques.

To find such a specialist near you, go to the Foundation for Women's Cancer's national list at foundationforwomenscancer.org/find-a-gynecologic-oncologist/

Questions to ask a doctor early in treatment

The National Cancer Institute suggests a patient might ask a doctor the following questions before starting treatment:

- What is the stage of my cancer? Has the cancer spread from the ovaries to other areas of my body? If so, where?
- What are the ways to treat my stage of cancer? What are the benefits and risks of each?
- How many chemotherapy sessions will I need? How long is each session?
- When will I need to start treatment?
- Will I need to be in the hospital for treatment? If so, for how long?
- Would a clinical trial (research study) be right for me?
- Can I get chemotherapy at my local hospital since it is too far to get to a major medical center?
- Will my insurance cover the cost of treatment?
- How will the treatment affect my normal activities?
- What are my chances of recovery with this treatment?
- Will the treatment cause me to go through early menopause?
- Will I be able to get pregnant and have children after my treatments?
- How often will I need to go for checkups after my treatment ends?

If you don't feel comfortable with a doctor, or want to get a second opinion about treatment options, you have the right to do this. In fact, most medical professionals expect a patient to get a second opinion.



Our Mission

The Rhode Island Ovarian Cancer Alliance's mission is to promote awareness and education about the signs, symptoms and risk factors of Ovarian Cancer. The organization is committed to providing support to women who have been diagnosed with Ovarian Cancer and their family members.

How you can help?

Your donation helps us increase awareness and continue our vital work to support Ovarian Cancer survivors and their families. No gift is too small and we appreciate your support in helping us save women's lives! To learn more about how to donate visit www.riovarian.org

We're here for you

If there's anything we can do to help you manage the challenges of Ovarian Cancer, please call 401-400-0333 or go to our website at riovarian.org

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