

# WHAT EVERYONE SHOULD KNOW ABOUT OVARIAN CANCER





# ABOUT THE NATIONAL OVARIAN CANCER COALITION®

Since 1991, the National Ovarian Cancer Coalition (NOCC) has supported thousands of cancer survivors, delivered millions of educational resources, and connected with dedicated local community members to raise awareness about ovarian cancer. The NOCC is a national advocate for patients, survivors, caregivers, and their families navigating their ovarian cancer iourney and remains steadfast in its mission "to save lives through the prevention and cure of ovarian cancer, and to improve the quality of life for survivors and caregivers." At the NOCC, our teal team leads with our values and unique experiences to provide support and education across all communities, ensuring that every person is empowered to advocate for their health.

#### **OUR MISSION**

To save lives through the prevention and cure of ovarian cancer and to improve the quality of life for survivors and their caregivers.

#### **OUR VISION**

We envision a future where no one ever loses their life to ovarian cancer.

## **OUR VALUES**

Connection, inclusivity, perseverance, authenticity, compassion, empowerment



## Ovarian cancer is overwhelming; finding credible, easy-to-understand information shouldn't be.

You will find a wealth of easy-to-understand information within these pages, from knowing the symptoms and risk factors to learning about diagnostic tests and treatment options.

By reading this booklet, you should be able to have meaningful discussions with your healthcare team. This knowledge will help you take an active role in your health, making sure your voice is heard and any concerns are addressed.

This booklet is not just about providing you with information. It's about creating a caring and supportive community. Together, let us strive for a world where no one ever loses their life to ovarian cancer

### Follow Us on Social!











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# Looking for Ovarian Cancer Resources at Your Fingertips?

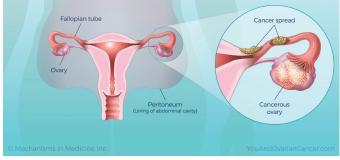


Visit **ovarian.org** today for the programs, resources, and tips you need to support your ovarian cancer journey.

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#### What is Ovarian Cancer?

The term "ovarian cancer" is often used to describe cancers that begin in the cells of the ovary, fallopian tube, or peritoneum. Ovaries are two small reproductive organs about the size of an almond or slightly larger—located on each side of the uterus. The ovaries make female hormones and eggs. Ovarian cancer is the fifth leading cause of gynecologic cancer deaths. Ovarian cancer mainly develops with older age and is more common in white individuals than in Black or African American individuals.



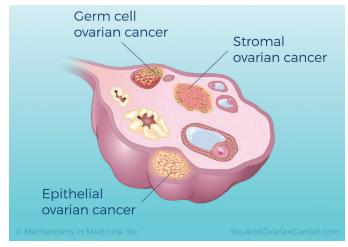
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There are many types of ovarian cancer. The most common type is called **epithelial ovarian cancer**. This type of ovarian cancer is found in the lining or outer surface of the ovaries.

#### Other types of ovarian cancer include:

- Germ cell tumors germ cells produce the eggs (ova); some tumors can form in these cells
- Sex cord stromal tumors are tissue
   cells that provide structure to the ovary
   to hold it together, and some ovarian
   tumors can form in this tissue. These
   cells produce hormones like estrogens
   and androgens (other sex hormones).

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## There are many sub-types of ovarian cancer, including:

- Serous carcinomas (low-grade serous and high-grade serous)
- Endometrioid carcinoma
- · Clear cell carcinoma
- Mucinous carcinoma
- Immature teratomas
- Dysgerminomas
- Endodermal sinus tumors (yolk sac tumor)
- Choriocarinomas
- Embryonal carcinoma
- Granulosa cell tumor
- Sertoli-Leydig cell tumor
- Small cell ovarian cancer

## What are the Symptoms of Ovarian Cancer?



BLOATING



PELVIC OR ABDOMINAL PAIN OR PRESSURE



TROUBLE EATING OR FEELING FULL QUICKLY



FEELING THE
NEED TO URINATE
URGENTLY OR OFTEN



**FATIGUE** 



UPSET STOMACH, HEARTBURN, OR CONSTIPATION



**BACK PAIN** 



DURING SEX



MENSTRUAL CHANGES

These symptoms are common and may not be related to ovarian cancer. Talk to your doctor if these symptoms are new and continue for more than two weeks. If cancer is a concern, a gynecologic oncologist should be seen.

## **DID YOU KNOW**

- Anyone born with ovaries is at risk for ovarian cancer.
- Knowing your risk and the signs and symptoms can help you make informed healthcare decisions.
- Symptoms can be vague but continue and increase over time.
- A Pap test DOES NOT detect ovarian cancer.

## What Increases the Risk of Ovarian Cancer?

Having one or more risk factors may increase ovarian cancer risk, but it does not mean ovarian cancer will develop. Some factors that can increase risk include:

- Having a personal or family history of breast, ovarian, or colorectal cancer
- Inheriting a genetic mutation (or gene change)
- Increasing age affects all ages, but most aged 55+ when diagnosed
- Never having a full-term pregnancy or having children later in life
- Long-term use of hormone replacement therapy (HRT) or infertility treatment
- Obesity
- Smoking

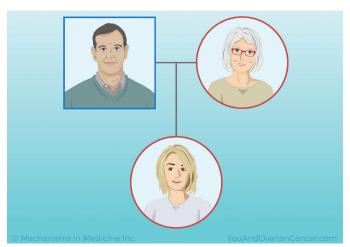
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## Is Ovarian Cancer More Common in Some Families?

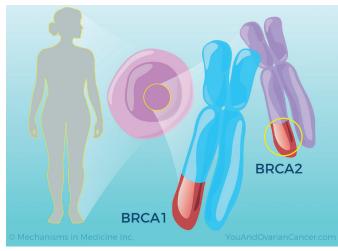
If your mother, sister, or daughter (first-degree relative) has had ovarian cancer, you may be at higher risk. This risk can come from both your father's or mother's side of the family.

A family history of other types of cancer, such as breast and colorectal cancer, is also linked to an increased risk of ovarian cancer. Talking to your family about your family health history is an important step in learning about your risk.

Ovarian cancer is sometimes part of an inherited cancer syndrome. The most common inherited cancer syndrome related to ovarian cancer is **hereditary breast-ovarian cancer syndrome or HBOC**. Those with HBOC often have mutations (changes) in the **BRCA1** and **BRCA2** genes.



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Studies show that inheriting a mutation in either gene can increase ovarian cancer risk. All people have these genes. Usually, these genes help to prevent cancer, but when these genes mutate or change, the risk for ovarian and breast cancer increases. Those of Ashkenazi (Eastern European) Jewish descent have a higher risk for ovarian cancer because they often have a higher risk of carrying BRCA mutations. Other gene mutations (*ATM*, *BRIP1*, *RAD51C*, *RAD51D*, and *PALB2*) have also been linked to a higher risk for the disease

**Lynch Syndrome** is another inherited cancer syndrome caused by mutations in 5 genes. The risk of ovarian cancer is higher than in those without the syndrome.

If you have one of these syndromes, talk to your doctor to better understand your risk and make a plan. This information can also help family members learn about their risk of ovarian and other cancers. Sharing your family medical history on both sides of the family can help identify genetic conditions that increase cancer risk.

## How Can I Reduce My Risk of Ovarian Cancer?

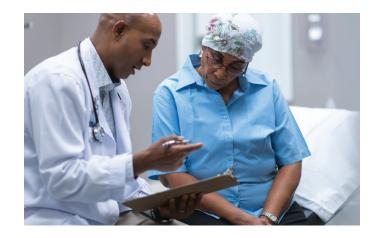
Currently, there is no way to prevent ovarian cancer, but here are some ways you can help reduce your risk:

**Use birth control** - Birth control pills can reduce the risk of ovarian cancer, especially for those who use them for five or more years.

**Breastfeeding and pregnancy** - Having one or more children and breastfeeding may decrease risk.

**Consider surgery** – The types of surgery listed below may reduce the risk of ovarian cancer. Talk about these with your doctor:

- Tying the fallopian tubes (tubal ligation)
   and removing the uterus (hysterectomy)
   may reduce the chance of certain types of
   ovarian cancer. These should only be done
   for valid medical reasons.
- Removing one or both of the ovaries (salpingo-oophorectomy) may be an option to reduce risk.
- Removal of the fallopian tubes only
   (opportunistic salpingectomy) can
   be done for those not at increased risk.
   This should only be considered for those
   already scheduled for a pelvic surgical
   procedure (i.e., tubal litigation,
   hysterectomy, cyst removal,
   endometriosis) and who have
   finished having children.



## How is Ovarian Cancer Diagnosed?

There is no accurate test to screen for or detect ovarian cancer today. The Pap test does not screen for ovarian cancer; it screens for cervical cancer. If ovarian cancer is a concern, the tests below can help find it:

- Pelvic exam the uterus, vagina, ovaries, bladder and rectum are checked for any unusual changes such as a mass.
- Annual rectovaginal exam physician inserts fingers in the rectum and vagina to feel for abnormal swelling and to detect tenderness.
- Transvaginal ultrasound a probe is inserted into the vagina to look at the female reproductive organs. It can often show abnormal areas of concern on the surface of the ovaries and within cysts that form in the ovaries.



- Blood tests Blood tests can be done to check for high blood levels of a protein called CA-125. This protein is sometimes produced and can be found more in ovarian cancer patients. Those with a high CA-125 level are often referred to a gynecologic oncologist. The CA-125 can be elevated due to many other conditions unrelated to ovarian cancer.
- Imaging tests Tests such as CT
   (computerized tomography), PET (positron
   emission tomography), or MRI (magnetic
   resonance imaging) may be used to show if
   any mass (tumor) is present.
- Biopsy A biopsy is the surgical removal of tissue to check for cancer. It is usually done during surgery when removing a mass.

If any of these tests suggest ovarian cancer, you should consult a gynecologic oncologist. A cancer specialist will look at your test results and decide on next steps. The most accurate way to confirm an ovarian cancer diagnosis is removing tissue and looking at it under a microscope. This is done through biopsy and surgery.

## **How is Ovarian Cancer Treated?**

Because each person's cancer is different, it is important to talk about the different kinds of treatment options with one's doctor. Treatment options depend on the tumor type, location, and stage of the cancer. It also depends on your age and overall health. Treatment for ovarian cancer includes:

**Surgery** - Surgery to remove the cancer is the main way to diagnose and treat ovarian cancer. It is best done by a qualified gynecologic oncologist. The goal is to remove as much tumor as possible (debulking).

**Chemotherapy** - Chemotherapy uses certain drugs to kill ovarian cancer cells. It is usually given intravenously (through a vein) after surgery but can also be given before surgery to shrink the tumor.

**Targeted Therapy** – Targeted therapy uses specific drugs designed only to attack and target cancer cells and stop them from growing and spreading. (PARP inhibitors are a type of targeted therapy also called poly [ADP-ribose] polymerase inhibitor).

**Hormone Therapy** – Hormone therapy uses hormones or hormone-blocking drugs to slow or stop the growth of cancer cells.

Radiation Therapy - Radiation therapy uses high-energy X-rays to kill cancer cells and shrink tumors. It is rarely used in the treatment of ovarian cancer.

Clinical Trials - Clinical trials are studies of new treatments. They are used to test whether new medicines are safe and more effective than existing ones. By enrolling in a trial, new treatments may be accessed. Ask your doctor if a clinical trial is right for you.



# What is the General Outlook for Those Diagnosed with Ovarian Cancer?

As we gather more information from research, we learn more about how the different types of ovarian cancers behave.

Due to the many types of ovarian cancer, every patient may have a different experience. The outlook will depend on many things, including the tumor type and stage, one's age, and overall health. Some ovarian cancers are hard to treat and grow quickly, no matter what stage they are found in. It has been stated that if diagnosed and treated when the cancer is confined only to the ovary, the five-year relative survival rate is over 90%.

Unfortunately, ovarian cancer symptoms are vague, and there is no effective screening for early detection of the disease. As a result, only 20% of all ovarian cancer cases are caught at an early stage. It is hard to predict an individual's outlook based on survival rates alone, as factors like overall health, cancer grade, and response to treatment can affect a patient's prognosis.

## SEE A GYNECOLOGIC ONCOLOGIST

Research has shown that patients treated by a gynecologic oncologist have better outcomes. Gynecologic oncologists are not only skilled surgeons, but they have extensive and specialized training in prescribing appropriate treatment and care for cancers of the female reproductive organs.

You can find a gynecologic oncologist by searching the Foundation for Women's Cancer's national list at www.foundationforwomenscancer.org

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# REFUSE TO Just breathe



In addition to this booklet, there are other ways to find support through the NOCC.

Our programs, resources, and patient services can support you wherever you are on your cancer journey.



To learn more about NOCC's programs and services, visit **ovarian.org** 

## NOCC PROGRAMS & SERVICES

#### PEER SUPPORT PROGRAMS

- Survivor Peer Support Groups –
   Teal Hearts Network
- Caregiver Support Group –
   Teal Cares Network

#### ONLINE EDUCATION PROGRAMS

- Animated Video Series YouandOvarianCancer.com
- Facebook Live Expert Interviews –
   Ask the Experts
- Wellness Series –
   Online Wellness Symposiums

#### SUPPORT SERVICES

- Cancer Care Package –
   Faces of Hope<sup>®</sup>
- Meal Delivery Service Teal Comfort for the Soul
- Emotional and Mental Health Support –
   Teal Comfort for the Mind
- Financial Assistance Program NOCC Treatment and Clinical Trial Funds

#### **COMMUNITY OUTREACH & EVENTS**

- National Run/Walk Series Together in TEAL®
- NOCC Signature DIY Program ROCK the Day®
- Endurance Awareness Events Team TEAL®
- Regional Education and Wellness Programs

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For more information, please contact us at:

NATIONAL OVARIAN CANCER COALITION 12221 Merit Drive, Suite 1950 | Dallas, TX 75251

> **1-888-OVARIAN** (1-888-682-7426) or 214-273-4200

> > nocc@ovarian.org ovarian.org