

# FRANKLY SPEAKING ABOUT CANCER

## Ovarian Cancer

Ovarian cancer is a cancer that begins in the ovaries or fallopian tubes. More than 21,000 women in the U.S. will be diagnosed with ovarian cancer this year.

Research advances have made significant strides in improving treatment options and survival for women with ovarian cancer. Yet, more than 75 percent of women are diagnosed with advanced ovarian cancer because there is no effective screening or early detection test and often the signs and symptoms women experience occur once the disease is advanced. The disease is often treated as a chronic condition because 85 percent of women who are diagnosed with ovarian cancer will have their disease return after finishing initial treatment. As a result, it is important to talk to your health care team about available treatment options and long-term side effects.



#### SUPPORT FOR FINDING INFORMATION ON OVARIAN CANCER

Facing Our Risk of Cancer Empowered (FORCE) 866-288-7475 [www.facingourrisk.org](http://www.facingourrisk.org)

National Cancer Institute 800-422-6237 [www.cancer.gov](http://www.cancer.gov)

Ovarian Cancer National Alliance (OCNA) 866-399-6262 [www.ovariancancer.org](http://www.ovariancancer.org)

# Risk Factors and Symptoms

While there is currently no effective early detection test available, there are some known risk factors that may increase a woman's chance of developing ovarian cancer. They include:

■ **FAMILY HISTORY AND GENETICS:** While it accounts for a limited number of cases, heredity is a strong risk factor for ovarian cancer. Women who have a mother, daughter or sister with ovarian cancer have an increased risk of the disease. Also, women with a personal or family history of cancer of the breast, prostate, pancreas, uterus, colon or rectum may also have an increased risk of ovarian cancer. BRCA1 and BRCA2 genetic mutations, those associated with Lynch Syndrome and other hereditary genetic mutations have been linked to an increased risk of developing ovarian cancer.

■ **AGE:** The average age of diagnosis for ovarian cancer is 63, but ovarian cancer can also occur in older and younger women.

■ **PREGNANCIES:** Women who have never been pregnant have an increased risk of ovarian cancer.

■ **MENSTRUATION:** More menstrual cycles/early menarche (first menstrual period) is associated with an increased risk of ovarian cancer.

■ **HOME REPLACEMENT THERAPY:** Women who use hormone therapy to alleviate symptoms of menopause may be at an increased risk for ovarian cancer.

“As an ovarian cancer survivor, and a daughter who lost her mother to what was probably metastasized ovarian cancer, I can’t emphasize enough the importance of knowing your family health history and seeking genetic counseling if there may be a hereditary component. Knowing if you carry a cancer-causing genetic mutation can inform treatment decisions and family members who may be at risk.”

— Tamara Combs, patient advocate

*Women with ovarian cancer report that symptoms are persistent and represent a change from normal functioning for their bodies.*

*The frequency and/or number of symptoms are key factors in the diagnosis of ovarian cancer.*

*Symptoms include:*

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

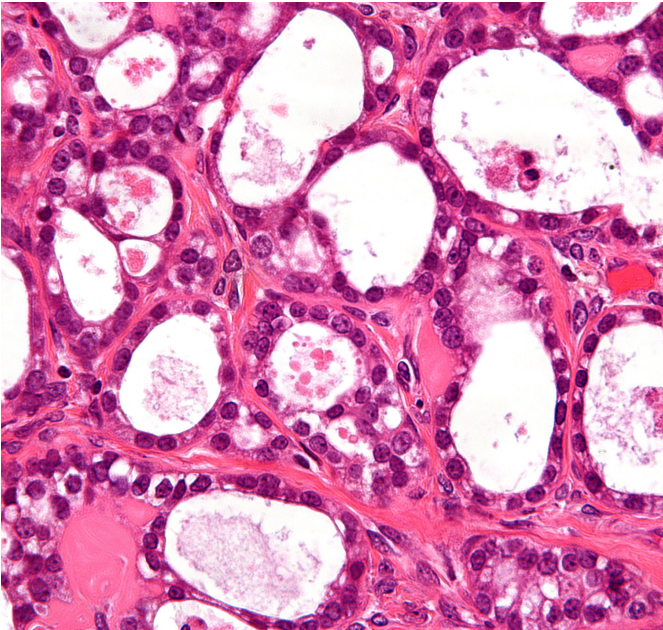
## WHAT IS CA-125?

CA-125 is a protein that ovarian cancer cells and some normal tissue produce. CA-125 is used to monitor patients after a diagnosis has been confirmed to track response to therapy. The levels usually go down if treatment is working. But, using CA-125 levels has not been found to be a reliable method for screening women. CA-125 is also associated with other diseases or conditions in women who do not have ovarian cancer and levels of this protein can fluctuate in women without ovarian cancer, leading to false positives and potentially unnecessary surgeries.

## Diagnosis and Staging

There are currently no early detection tests to diagnose ovarian cancer. If ovarian cancer is suspected, your doctor may perform a pelvic and rectal exam as part of a series of diagnostic tests, followed by a transvaginal ultrasound.

Once the surgical diagnosis is made, the tumor type, stage and grade of the cancer are used to determine the best treatment.



OVARIAN CANCER CELLS

### WHAT IS RECURRENCE?

*The American Cancer Society defines cancer recurrence as the return of cancer after treatment and after a period of time during which the cancer cannot be detected. The cancer may come back in the same area that it was first detected or another area of the body.*

Ovarian cancer has several different tumor types including: epithelial tumors, germ cell carcinoma tumors, stromal carcinoma tumors and small cell carcinoma of the ovary. Stages of ovarian cancer are classified as Roman numerals I-IV (1-4). The higher the number, the more the disease has spread:

#### ■ STAGE I

The cancer is confined to one or both ovaries.

#### ■ STAGE II

Ovarian cancer has spread to another area within the pelvis without spreading elsewhere in the abdomen.

#### ■ STAGE III

Cancer has spread from one or both ovaries to the lining of the abdomen or lymph nodes.

#### ■ STAGE IV

Ovarian cancer has spread beyond the abdomen to distant organs, such as the lung or liver.

There are three grades of ovarian cancer: Grade 1, Grade 2 or Grade 3. The lower the grade, the slower the cancer cells grow.

## Treatment Options

One of the many decisions you will make about your cancer treatment is choosing a doctor, a team and a cancer center that has the expertise to treat your ovarian cancer. It's critical to feel confident in the people who are treating you and to be able to communicate with them. Remember you can always seek a second opinion or change doctors if your situation changes and you need a different level of care.

Treatment for ovarian cancer depends on the stage of cancer, whether or not you have symptoms, your overall health and genetic mutations, such as BRCA. Treatment includes a combination of options, often starting with surgery, then chemotherapy and possibly, in rare cases, radiation therapy. Other potential treatments being evaluated in clinical trials include immunotherapy, gene therapy and hormone therapy. It is also important to learn about the potential side effects of each treatment before deciding which course of action to take and how you will work with your health care team to manage any side effects you experience.

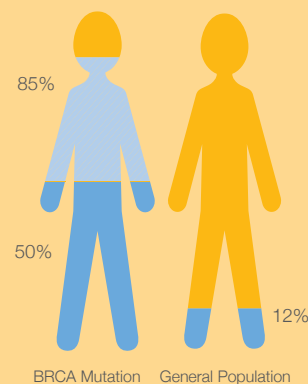
“Consider a consultation with a gynecologic oncologist at a cancer center. If it's not conveniently located for you seek a second opinion closer to home. Some women may find it helpful to speak with others who have been through similar experiences. Your doctors or nurses will be able to provide you with different resources.”

– Latasha Anderson-Dunkley, ANP, RN

### GENETIC COUNSELING AND TESTING

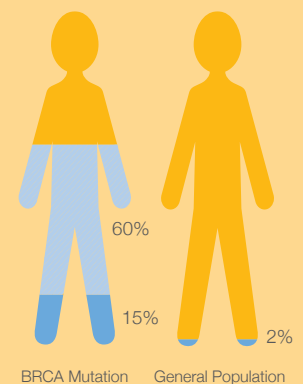
The Society of Gynecologic Oncology and National Comprehensive Cancer Network recommend that any woman diagnosed with ovarian, fallopian tube or peritoneal cancer—regardless of age or family history—receive genetic counseling and be offered genetic testing. Knowledge of a hereditary genetic mutation associated with increased risk of cancer can help guide treatment and surgical decisions, in addition to informing family members about their potential risk of certain cancers. Pre- and post-test counseling is essential to understanding genetic testing options and results. Genetic counseling and testing can be conducted by a genetic counselor or other knowledgeable medical professionals. Genetic testing in epithelial ovarian cancer patients is considered “medically necessary” and is covered by most insurance providers.

#### BREAST CANCER



Women with the BRCA mutation have a 50-85% risk of developing breast cancer during their lifetime. By comparison, women in the general population only have a 12% lifetime risk of the disease.

#### OVARIAN CANCER



The risk of ovarian cancer also increases to 15-60% for women with the BRCA mutation, compared to the general population risk of 1-2%.

## QUESTIONS FOR YOUR HEALTH CARE TEAM

- WHAT IS MY TUMOR TYPE?
- WHAT ARE MY TREATMENT GOALS? (IS IT TO CONTROL THE CANCER, MANAGE SYMPTOMS OR SOMETHING ELSE?)
- WHAT CAN I EXPECT FROM TREATMENT, HOW LONG WILL IT LAST AND WHAT WILL I EXPERIENCE?
- WHAT KIND OF SIDE EFFECTS CAN I EXPECT?
- WILL TREATMENT IMPACT INTIMACY IN ANY WAY?
- HOW LONG WILL SIDE EFFECTS IMPACT MY LIFESTYLE AND WHAT CAN BE DONE TO MANAGE POTENTIAL SIDE EFFECTS?
- WHAT SUPPORT SERVICES ARE AVAILABLE TO ME AND MY FAMILY?
- WHO WILL BE THE MEMBERS OF MY HEALTH CARE TEAM? IF I SEE A NUMBER OF DIFFERENT PEOPLE, WHO IS MY PRIMARY CONTACT?
- I UNDERSTAND THAT OVARIAN CANCER CAN RECUR, EVEN AFTER TREATMENT. WHAT IS THE LONG-TERM PLAN FOR MY CARE?
- IF I HAVE QUESTIONS ALONG THE WAY, WHAT IS THE BEST WAY TO CONTACT MY DOCTOR OR NURSE FOR QUICK ANSWERS OR NURSE FOR QUICK ANSWERS?
- HOW DO I GET HELP WITH MANAGING THE COST OF MY CANCER CARE?

## Surgery

This procedure involves removing as much of the tumor as possible. It is very important to have surgery performed by a trained doctor known as a gynecologic oncologist. Contact the Society of Gynecologic Oncology or visit their website, [www.sgo.org](http://www.sgo.org) to find a list of trained gynecologic oncologists in your area.

“Gynecologic oncologists are doctors with special training in the management of women with gynecologic cancers, including ovarian cancer. Studies show that outcomes, including survival, are better for women with ovarian cancer under the care of gynecologic oncologists.”

—Marcela Del Carmen, MD

## Chemotherapy

After surgery, most women with ovarian cancer receive drugs to kill any remaining cancer cells. The most common combination of chemotherapy for ovarian cancer is a platinum compound such as carboplatin or cisplatin plus a taxane, such as paclitaxel (Taxol®) or docetaxel (Taxotere®). Other chemotherapy drugs used to treat ovarian cancer include: Albumin bound paclitaxel (nab-paclitaxel, Abraxane®), Altretamine (Hexalen®), Capecitabine (Xeloda®), Cyclophosphamide (Cytosan®), Etoposide (VP-16), Gemcitabine (Gemzar®), Ifosfamide (Ifex®), Irinotecan (CPT-11, Camptosar®), Liposomal doxorubicin (Doxil®), Melphalan (Alkeran®), Pemetrexed (Alimta®), Topotecan (Hycamtin®) or Vinorelbine (Navelbine®). Lynparaza™, also known as olaparib, is a type of PARP inhibitor therapy which is currently an option for women with BRCA mutations who have recurrent disease.



## New Treatments for Ovarian Cancer

Since we wrote our *Frankly Speaking About Cancer: Ovarian Cancer* booklet in 2015, the FDA has approved new targeted therapy drugs for ovarian cancer. Targeted therapy may be an option for some patients with ovarian cancer. Targeted drugs aim to block cancer growth “driven” by changes to the tumor’s genes (DNA). Some targeted therapies have biomarker tests that your doctor can order. These tests predict how well your cancer may respond to the targeted therapy. Targeted therapy may have different side effects than chemotherapy.

Bevacizumab (Avastin®) is being used with chemotherapy for advanced stage cancers. It works by targeting blood vessels so they cannot feed growth of the tumor. Bevacizumab can be used during initial treatment or to treat the cancer if it returns. When used during initial treatment, this drug is given after surgery to remove cancerous tissue.

Several other drugs, called PARP inhibitors, are used in maintenance therapy or as treatment if the cancer recurs. Maintenance therapy when given after the cancer returns is offered to patients whose tumors have already shown a response to treatment. It can delay the amount of time it takes for the cancer to start to grow again. Rucaparib (Rubraca®), niraparib (Zejula®), and olaparib (Lynparza®) are examples of PARP inhibitors.

If you have advanced ovarian cancer, ask your doctor about these treatment options.



## Intraperitoneal Chemotherapy

This procedure involves a surgically implanted port or catheter to direct chemotherapy into the membrane lining the abdomen. Intraperitoneal (IP) therapy is combined with intravenous (IV) therapy, using chemotherapy drugs that work best for treating ovarian cancer. IP therapy may be difficult on patients, and some may not be able to complete all six cycles of the therapy. But research has shown IP to be an effective treatment option, so talk to your gynecologic oncologist about whether or not this treatment option is right for you.

## Common Side Effects and Tips for Side Effect Management

It is helpful to work with your health care team to address side effects from treatment to help maintain your quality of life. Don't be afraid or embarrassed to tell your doctors what is going on with your body, including any pain or discomfort you may be feeling. Common side effects from treatment include: hair loss, nausea, nerve pain (neuropathy), fatigue, diarrhea or constipation, swelling of limbs (lymphedema) and sexual side effects.

Whether it is nausea, hot flashes or discomfort with intercourse, there are many options that can help you cope with the effects of treatment. The key is to talk with your health care team so that you can work together and find effective ways to make the treatment experience as tolerable as possible.

## Eating Well During and After Treatment

It is very important to maintain good nutrition during and after treatment to help manage side effects and aid in recovery. Although you may not feel up to it, eating well during treatment can help you tolerate treatment and feel better. Excess weight loss can cause treatment delays.

Nausea, vomiting, decrease in appetite, diarrhea and fatigue are common challenges for many women with ovarian cancer and create barriers to meeting nutritional goals. It may help to eliminate food with strong odors and trying cold food, which have fewer odors. Many women find that they are able to tolerate these foods better. Focusing on bland foods that are high in calories and protein, and eating frequent, small portions can also be helpful for women who experience nausea. Try to avoid fried, greasy, spicy and overly sweetened foods, which can trigger nausea.

As treatment for ovarian cancer progresses, it is likely that your schedule will be very busy with different appointments, and it may be easy to skip meals. It is important to remember to eat in order to maintain strength and energy. Not eating can result in nausea when taking medication. If fatigued, be sure to get enough fluid and meet nutritional needs. Supplement drinks may be used as an option if eating is difficult, but it is important to talk with your health care team and try different approaches to find what may or may not work in finding foods and textures that appeal to you during and after treatment.

“I have side effects, but my health care team and I take care of them, some will remain but they are manageable.”

—Donna, living with ovarian cancer

## Living with Ovarian Cancer

Being diagnosed with cancer can feel very isolating and distressing. “There are also social and emotional factors related to an ovarian cancer diagnosis, including a loss of control, loss of hope, loneliness and anxiety in living with uncertainty,” says Kelly Schoen, MSW, LISW-S, Program Director at Cancer Support Community Greater Cincinnati-Northern Kentucky. Because ovarian cancer can also recur, “women can be left with additional feelings of anxiety or stress even after treatment is complete.”

Be sure to bring up these concerns with your doctor, especially if you have symptoms that affect your quality of life. “Being able to express your feelings with others is an important part of coping and helps normalize the range of emotions that come with a diagnosis,” says Schoen. Women with ovarian cancer can find a support group and talk with other people who share similar experiences or speak with a counselor or social worker about the challenges of living with cancer. A counselor or social worker can help you cope by providing tips on making changes to improve your quality of life, learning to live with uncertainty, managing expectations and taking a proactive approach to treatment and symptom management.

After being diagnosed with ovarian cancer, your friends, family and neighbors may want to show support. “Most people will want to help, but may not know how to help or what to do to show their support. It may be beneficial to think about the things that your friends, family, neighbors and co-workers can do based on their availability and skills, and let them know what would help.” As others help, try to be patient when they can’t provide assistance—and seek “back-up” support. Unfortunately, it is common that some family and friends may “disappear.” Try not to take this personally, often family and friends do not know what to do and fear doing or saying the wrong thing.

IF YOU FEEL OVERWHELMED  
OR ARE UNSURE OF WHAT  
TO ASK PEOPLE TO DO, BELOW  
ARE SOME QUESTIONS  
THAT MAY HELP:

- What type of help do I want?  
(Help with laundry or meals?  
Help with rides to medical  
appointments or?  
Help with children?)
- Who would I like to talk with  
about treatment decisions?  
Or join me at medical  
appointments?
- Who can help me with practical  
support, such as work leave,  
family care or driving, financial  
questions?
- What is important to me?
- What gives me joy?
- Can I make plans to do  
something I’ll look forward to?







## Donna's Experience

Donna finds hope in the treatment advances that are being made through cancer clinical trials. More than two and a half years ago, Donna was diagnosed with low grade ovarian cancer. Her particular cancer did not respond well to chemotherapy treatment, therefore Donna's doctors recommended that she consider joining a clinical trial. For Donna, it was a decision that came without hesitation, "it was pretty clear that the chemo wasn't working," she said. "This clinical trial gave me hope that I might find a treatment that works for me."

Living with ovarian cancer, comes with its own unique set of challenges. Along with physical side effects from treatment, which she is able to manage in partnership with her health care team, there are also emotional challenges that she must cope with daily. Donna was most

**"This is absolutely not a death sentence – there are so many options available today that were not available several years ago."**

—Donna, living with ovarian cancer

**"She realized that although she wanted to maintain her independence, there are instances when you will need help or support, and it is okay to ask."**

surprised by the emotional support that she received from her family and colleagues. "My husband has been amazing, my children have been wonderful, my sister checks up on me every day and although I am retired I still keep in touch with the people I worked with – emotional support is huge."

From a treatment point of view, Donna knows that as a patient, it is essential to be as informed as possible about your cancer and its treatment, and to work closely with your health care team in order to make the best possible decision. From a personal point of view, she states, "there are people who really care and want to help." She realized that although she wanted to maintain her independence, there are instances when you will need help or support, and it is okay to ask.

### **ARE THERE CLINICAL TRIALS FOR OVARIAN CANCER?**

*Clinical trials (research studies) may give you access to new treatments for ovarian cancer, at any stage. Some studies test new ways to use drug combinations, doses or techniques that are already approved, while others test completely new and hopeful techniques. Your doctor can help you determine which clinical trial is right for you.*

# Resources for Ovarian Cancer Information & Support

American Cancer Society 800-227-2345 [www.cancer.org](http://www.cancer.org)

Cancer Legal Resources Center 866-843-2572 [www.cancerlegalresourcescenter.org](http://www.cancerlegalresourcescenter.org)

Facing Our Risk of Cancer Empowered (FORCE) 866-288-7475 [www.facingourrisk.org](http://www.facingourrisk.org)

National Cancer Institute (NCI) 800-422-6237 [www.cancer.gov](http://www.cancer.gov)

NCI's Clinical Trials Registry 888-422-6237 [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)

Ovarian Cancer National Alliance 866-399-6262 [www.ovariancancer.org](http://www.ovariancancer.org)

Patient Access Network Foundation 866-316-7263 [www.panfoundation.org/ovarian-cancer](http://www.panfoundation.org/ovarian-cancer)

Patient Advocate Foundation 800-532-5274 [www.patientadvocate.org](http://www.patientadvocate.org)

SHARE 866-537-4273 [www.sharesupport.org](http://www.sharesupport.org)

## CANCER SUPPORT COMMUNITY RESOURCES

To access any of the free resources below call 1-888-793-9355 or visit [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org).

### CANCER SUPPORT HELPLINE®

Whether you are newly diagnosed with cancer, a long-time cancer survivor or caring for someone with cancer, CSC's toll-free Cancer Support Helpline (1-888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you Mon-Fri 9am- 9pm ET.

### OPEN TO OPTIONS®

If you are facing a cancer treatment decision, this research-proven program can help you. In less than an hour, our trained specialists can help you create a written list of specific questions about your concerns for your doctor.

### AFFILIATE NETWORK SERVICES

Over 50 locations plus more than 100 satellite locations around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer.

### CANCER EXPERIENCE REGISTRY®

The Registry is a community of people touched by cancer. The primary focus of the Registry is on collecting, analyzing and sharing information about the experience and needs of patients and their families. To join, go to [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

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