



Foundation  
for Women's Cancer



# OVARIAN CANCER

Your Guide

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As a patient or caregiver, the amount of information you receive at the time of a diagnosis of ovarian cancer can feel overwhelming. All at once, you may feel there are many unanswered questions, decisions to be made, and so much information to review and understand.

A team of health care professionals will work with you and your family throughout your treatment and comprehensive ovarian cancer care. Each of them has an important job although the most vital member of the team is you.

This booklet will take you through the basics of ovarian cancer diagnosis and treatment. It will introduce you to the care provider specialists who may be part of your treatment team. Also, this guide will discuss the different types of treatments for ovarian cancer. This booklet is designed to help aid you and your support system in better understanding ovarian cancer and current treatments in order to play an active role in understanding your care.



# Ovarian Cancer: An Overview

Cancer occurs when cells in an area of the body grow abnormally. Ovarian cancer is the seventh most common cancer among women worldwide. It is important to understand that ovarian cancer is not just one disease and every patient's experience and specific treatments may differ. There are three major categories of ovarian cancer: epithelial ovarian cancer, germ cell cancer, and stromal cell cancer, and there are numerous types of epithelial and stromal cancers.

**Epithelial ovarian cancers** are the most common and account for 85% to 89% of ovarian cancers. They form from the surface cells of the ovary or from the fallopian tube surface cells. They rank fourth in cancer deaths among women in the U.S. and cause more deaths than any other cancer of the female reproductive system. Epithelial ovarian cancers can be a part of a hereditary or familial (genetic) syndrome such as those with *BRCA1* and/or *BRCA2* gene mutations. Fallopian tube and primary peritoneal cancers are also epithelial cancers and have identical behavior, risks and treatment strategies, so are included whenever epithelial ovarian cancer is discussed.

**Germ cell cancers** are less common forms of ovarian cancer, accounting for only about 5% of ovarian cancers. Germ cell cancers start in the cells that develop into follicles or eggs in the ovaries. This cancer is usually diagnosed in adolescents and young women, and often only affects one ovary.

Equally rare, **stromal cell cancers** start in the cells that produce female hormones and hold the ovarian tissues together. Similarly, there are several types of stromal cell cancers and presentation and treatment can vary.

## Symptoms and diagnosis

Historically, ovarian cancer was called the “silent killer” because symptoms were not thought to develop until the chance of cure was poor. However, recent studies have shown that many symptoms listed below, if new, persistent or worsening, are more likely to occur in women with ovarian cancer than in women in the general population. Even patients with early-stage disease may have these symptoms.

Symptoms of ovarian cancer can include:

### These symptoms include:

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

While these may be common symptoms many women without cancer may have occasionally, patients with ovarian cancer report that symptoms are persistent and often progressive, and represent a change from normal for their bodies.

The frequency and/or number of such symptoms are key to consider. Women who have these symptoms almost daily for more than a few weeks should see their doctor, preferably a gynecologist and have a pelvic (gynecologic) exam. Prompt medical evaluation may lead to earlier detection and more prompt diagnosis and treatment. Several other symptoms have been commonly reported by women with ovarian cancer.

These other symptoms include fatigue, indigestion, back pain, pain with intercourse, constipation or diarrhea, and menstrual irregularities. However, these other symptoms are also found in equal frequency in women in the general population who do not have ovarian cancer. Importantly, if a symptom does not go away and gets worse over time, a woman should be evaluated by a health care provider.

## Medical evaluation

When a person experiences concerning symptoms, a pelvic (gynecologic) exam and a general physical exam should be performed. Based on the findings of the exam, imaging of the pelvis with a pelvic ultrasound is often recommended if there is a mass or cyst felt on exam. Even if the exam is normal, women may be recommended to undergo a pelvic ultrasound to evaluate the ovaries.

If an abnormality of the ovaries is found or if the physical exam or symptoms are more concerning, additional imaging tests such as a CT scan or an MRI may be ordered to help your provider understand more about what is happening elsewhere in the body.

Often if there is a mass or complex cyst or something abnormal on the ovaries, blood tests known as tumor markers may be ordered, such as a blood test for a protein called CA 125. Keep in mind that CA 125 is not approved for this use, and is only useful at best for serous cancers.

CA 125 should not be used as a routine screening test, but may help your provider in the work up of a cyst or mass. CA 125 can be elevated in approximately 80% of women with advanced-stage epithelial ovarian cancer, but elevations can occur also for reasons other than ovarian cancer especially in women before menopause. For more information, please visit [foundationforwomenscancer.org](http://foundationforwomenscancer.org) for a brochure entitled **CA 125 Levels: Your Guide**.

CA 125 is less likely to be elevated in some of the other less common ovarian cancer types (germ cell or stromal cell cancers). Other tumor markers blood tests for these cancer types may be ordered based on a patient’s age, symptoms and imaging findings.

# Working with your treatment team

During your treatment, you will meet many health care professionals. These people make up your treatment team. They will work with each other and you to provide the special care you need. Your treatment team may include some of the health care professionals listed below.

**Gynecologic oncologists** are board-certified obstetrician-gynecologists who have an additional three to four years of specialized fellowship training in the complex surgery and medical treatment of gynecologic cancers. A gynecologic oncologist can manage your care from diagnosis and through completion of treatment and surveillance.

Studies show that patients treated by gynecologic oncologists at high-volume centers have improved outcomes. The experience and specialized training of gynecologic oncology surgeons allows more complete resection of the tumor at the time of surgery. Many gynecologic oncologists will also plan and administer the chemotherapy program and discuss best treatment options and clinical care.

To find a gynecologic oncologist in your area, log onto the Foundation for Women's Cancer website ([foundationforwomenscancer.org](http://foundationforwomenscancer.org)) and enter your zip code in the "Find a Gynecologic Oncologist" section.

## You also may be treated by:

**Medical oncologists** who specialize in using drug therapy (chemotherapy) to treat cancer. Many medical oncologists focus in the treatment of gynecologic cancers including clinical trials. Some medical oncologists will work closely as a team with your gynecologic oncologist to be able to provide chemotherapy closer to home.

**Radiation oncologists** who specialize in using radiation therapy to treat cancer. Radiation is used in rare, unique circumstances in the treatment of ovarian cancer.

Other health care professionals who will or may be part of your team:

**Oncology nurses** who specialize in cancer care. An oncology nurse can work with you on every aspect of your care, from helping you understand your diagnosis and treatment to providing emotional and social support.

**Social workers** who are professionally trained in counseling and practical assistance, community support programs, home care, transportation, medical assistance, insurance,



and entitlement programs. Social workers are very helpful advocates, especially when you are first diagnosed and unsure about what to do next.

**Palliative care providers:** Physicians and other care professionals trained in palliative and supportive care are an important resource for symptom management for anyone with ovarian cancer and especially for those with advanced disease. They help with management of symptoms such as pain, nausea, sleep disturbances or discussions about advanced care planning are some commonly covered topics. While some patients choose to meet with palliative care specialists if there is a recurrence or worsening symptoms, it is recommended to consider early consultation with this team for best control of symptoms related to the cancer or the treatments. Palliative care is not the same as hospice care which has a focus on supportive end-of-life care.

**Genetic counselors or medical geneticists:** Approximately 15-20% of ovarian cancers are caused by an inherited genetic

mutation. A genetic counselor or medical geneticist provides information to help you decide whether to undergo genetic testing (typically a blood test), what test to select, and how to interpret the results. Knowing whether you have a gene that put you at increased risk of developing ovarian cancer is important for cancer treatment decisions, other cancer risk management, and family member cancer risk decisions.

**Patient navigators** who educate patients about the disease and serve as an advocate on behalf of the patient and her caregivers throughout cancer treatment.

**Clinical trial/research nurses** if you are participating in a clinical trial. Clinical trials are necessary for finding new treatments and improving patient care. Clinical trial nurses play a key role in this research by ensuring patients' safety and offering support throughout the research study.

**Nutritionists or registered dietitians** who are expert in helping you maintain or initiate healthy eating habits. This

is important in the recovery process. These professionals can help you manage potential side effects of treatment such as poor appetite, nausea, or mouth sores. It is important to note that natural remedies and supplements should be taken only after consultation with your gynecologic or medical oncologist(s) to insure there are no reactions with your other medications or chemotherapy

**Psychologists or psychiatrists:** Many patients experience changes in mood and some may have significant depression, anxiety or other psychological concerns after a cancer diagnosis. These symptoms can be a very natural reaction to a major new stressor for anyone. While some patients may have a history of similar concerns, the diagnosis of ovarian cancer may worsen symptoms. For others, these symptoms may be new. Trained social worker, psychologists and social workers are a good resource to consider if you are experiencing distress or signs of depressed mood or anxiety. Often therapy and/or medications to help these conditions can help manage symptoms.

## Talking with your team

You deserve expert advice and treatment from your cancer care team. Be sure to talk openly about your concerns with the members of your treatment team. Let them know what is important to you. If it is hard for you to speak for yourself, these tips may help:

- Make a list of questions before your visit. Ask the most important questions first.
- Take notes or ask if you can record your medical office visits and phone conversations.
- If you don't understand something, ask the treatment team member to explain it again in a different way.
- If possible, bring another person with you when you meet with members of your treatment team to discuss test results and treatment options.
- Report how you feel and any side effects.
- If a family member or caregiver cannot attend in person, ask for options for telehealth (video or phone) visits.



# Ovarian cancer staging

When ovarian cancer is diagnosed, it is important to determine if the cancer has spread beyond the ovaries. Your treatment team may do more imaging tests and a biopsy or a surgery to determine the stage or where the cancer is located. Staging helps to determine the exact extent of your cancer and what treatment plan is best for you.

In some patients, imaging such as CT scan or MRI scan, can demonstrate spread of the cancer beyond the ovaries or pelvis and the gynecologic and medical oncologists on your treatment team may recommend getting a biopsy, piece of tumor, to confirm that you have ovarian cancer followed by initiation of medical treatment. This approach is called neoadjuvant chemotherapy. Surgery is generally put off until after three to four cycles of treatment.

If imaging such as a CT scan shows findings that suggest the cancer may have spread beyond the ovaries, a sample of cancer cells may be obtained through a CT-guided biopsy, ultrasound-guided fluid collection from the abdomen (paracentesis) or space between the lung and chest wall (thoracentesis), or through a laparoscopic surgery. The diagnosis of ovarian cancer must be confirmed by pathologists who look at the biopsies or fluid samples.

This information will also help to determine the order of the treatments your team has planned. If the extent of cancer is more advanced or in areas that are difficult to remove, medical (chemotherapy) treatment may be started first and a surgery performed later once tumors have shrunk. This approach is called neoadjuvant chemotherapy.

For some patients, a more extensive staging surgery can be performed first instead as part of both the staging and initial cancer treatment plan. This includes a surgery that removes the ovaries, uterus, possibly other organs such as sections of bowel, and ideally all of the visible tumor. This is often called cytoreductive or debulking surgery and is then followed by chemotherapy.

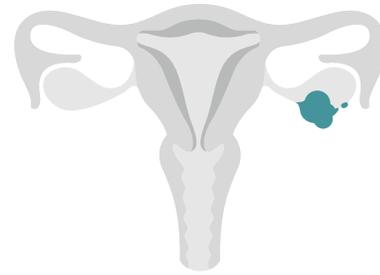
Your team will use all the information from the exam, imaging, biopsy results or any surgery to determine the stage of the cancer. Stages can include: Stage I, II, III, or IV, as illustrated on the following page. The cancer tissue collected will also be assigned a grade. Grade refers to how abnormal the cells appear under a microscope. Low grade tumors, also called grade 1, have features that resemble normal ovarian cells and tend to be slower growing cancers. In contrast, in high grade tumors (grade 3) the microscopic appearance is greatly altered from normal and these cancer cells tend to grow at a faster rate.

It is important that your staging and/or debulking surgery be performed by a gynecologic oncologist, a physician with special training in the care of ovarian cancers. Studies show that patients treated by gynecologic oncologists at high-volume centers have improved outcomes.

# Ovarian cancer stages

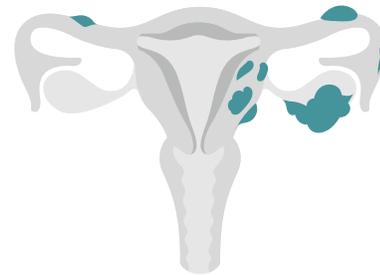
## Stage I

The cancer is found in one or both ovaries. Cancer cells also may be found on the surface of the ovaries or in fluid collected from the abdomen.



## Stage II

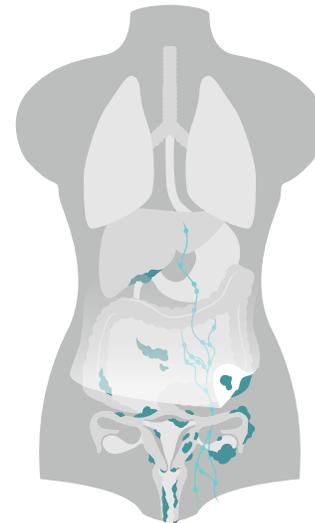
The cancer has spread from one or both ovaries to other tissues in the pelvis, such as the fallopian tubes or uterus or surfaces of the bladder or pelvis.



Cancer cells may also be found in fluid collected from the abdomen.

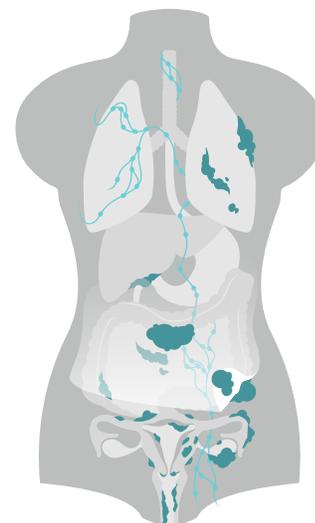
## Stage III

The cancer has spread outside the pelvis or nearby lymph nodes. Most commonly the cancer spreads to the omentum (an apron of fatty tissue that hangs down from the colon and stomach), diaphragm, intestine, and the outside (surface) of the liver.



## Stage IV

The cancer has spread to tissues outside the abdomen and pelvis. The most common place for the cancer to spread is in the space around the lungs. Additionally, if the cancer spreads inside the liver or spleen or inside the lungs, it is considered stage IV.





# Treatment types & side effects

Ovarian cancer is most often treated with surgery and chemotherapy. Whether surgery or chemotherapy is used first will depend on several factors specific to your disease. Only rarely is radiation therapy used. It is important to distinguish between early-stage ovarian cancer and advanced disease because the treatment approaches are different. Different ovarian cancer types may also have different treatments.

All treatments for ovarian cancer have side effects. Most side effects can be managed. Treatments may affect unexpected parts of your life, including your function at work, home, intimate relationships, and deeply personal thoughts and feelings.

Before beginning treatment, it is important to learn about the possible side effects, and talk with your treatment team members about your feelings or concerns. They can prepare you for what to expect and tell you which side effects should be reported to them immediately. They can also help you find ways to manage the side effects that you experience.

## Cytoreductive and staging surgery

Surgery is often the first step in treating ovarian cancer and it should be performed by a gynecologic oncologist. In order to thoroughly explore the abdomen and pelvis, most of the time ovarian cancer surgery is done through an open, large, laparotomy incision. The surgeon makes an up and down incision along the midline of the abdomen. Through this open incision, organs affected by ovarian cancer including the ovaries, tubes, uterus are surgically removed, cancer masses are removed, and/or additional biopsies or removal of lymph nodes are performed. This also determines the surgical stage of the cancer.

Select cases of very early appearing ovarian cancer can be surgically staged using minimally invasive surgery (robotic or laparoscopic) by using a camera and multiple small incisions on the abdomen. This approach can also be performed for very select patients with advanced ovarian cancer who have had an excellent response to neoadjuvant chemotherapy.

If ovarian cancer is found, the gynecologic oncologist usually performs the following procedures:

**Salpingo-oophorectomy:** Both ovaries and fallopian tubes are removed.

**Hysterectomy:** The uterus is removed.

**Staging procedure:** Including omentectomy, lymph node removal.

**Omentectomy:** Removal of a pad of fat that hangs from the large intestine is removed as it often contains tumors.

**Lymph node dissection:** In cancers that appear early and limited to the ovaries, lymph nodes are removed to test for microscopic disease. In those cancer that are more advanced, lymph nodes that are enlarged and worrisome may be removed.

**Debulking:** Removal of any additional visible disease.

Sometimes ovarian cancer debulking also requires removal of other involved organs such as the appendix or spleen, or portions of other involved organs such as the small or large intestine. Removal of as much tumor as possible and ideally all visible tumor is one of the most important factors affecting ovarian cancer outcomes.

Your gynecologic oncologist will discuss what surgical procedures are expected based on preoperative imaging.

# Fertility sparing surgery:

If you are diagnosed with probable stage I cancer and still hope to get pregnant, it may be possible to only remove one ovary and fallopian tube during your staging surgery. Your future pregnancy wishes should be discussed with your gynecologic oncologist before surgery and often depend on the stage and cell type of the cancer. Consulting with a specialist in fertility (onco-fertility or reproductive endocrinology) is important to consider as well.

## Goals of surgery

It is important to understand the goals of surgery. These goals may fall into any of the following categories.

1. Cytoreductive (debulking) surgery to remove as much cancer as possible — the best outcome is if the surgeon can remove all visible cancer. In some cases, your surgeon may want start with a laparoscopy to look inside to determine if the cancer can be optimally removed. In this case, the surgeon may proceed with the full operation at the same time or stop and schedule a more extensive surgery before chemotherapy.
2. Diagnostic surgery to obtain a tissue biopsy and/or assess whether a more extensive surgery is feasible. This is often accomplished through laparoscopy. If the cancer is not able to be optimally removed at initial diagnosis, your gynecologic oncologist will recommend starting with chemotherapy to shrink the tumor(s) so that they can be removed after a 3-4 treatment of neoadjuvant chemotherapy. This approach is called neoadjuvant chemotherapy. A larger more extensive interval cytoreductive surgery is generally put off until after 3-4 cycles of treatment allowing the chemotherapy to shrink many of the tumor areas. Often a more extensive staging surgery is performed.
3. Staging surgery is performed if there is only evidence on imaging of an ovarian mass suspicious for ovarian cancer. It is important to know that some non-cancerous masses of the ovary can mimic ovarian cancer. Surgery to remove the mass is often the only way to determine whether it is cancer or not cancer. If cancer is found during the surgery, then the additional steps of staging can be performed.

## Side effects of surgery

Some discomfort is common after surgery. It often can be controlled with medicine. Tell your treatment team if you are experiencing pain. Talk to your doctor if you are experiencing any other possible side effects, such as:

- Nausea and vomiting
- Fevers which can signal an infection
- Wound problems
- Fullness or bloating, which can be due to fluid in the abdomen
- Shortness of breath or chest pain which can be symptoms of blood clots, anemia or fluid around the lungs.
- Excess fatigue or lightheadedness or dizziness which could be caused by low red blood cells (Anemia) or other problems with electrolytes.
- Swelling and or pain in the legs which can be due to fluid retention or more seriously blood clots.
- Difficulty urinating or constipation

# Chemotherapy

Chemotherapy is the use of drugs to kill cancer cells. Chemotherapy for ovarian cancer is usually given intravenously (injected into a vein). You may be treated in the doctor's office or the outpatient part of a hospital or clinic.

The drugs travel through the bloodstream to reach all parts of the body. This is why chemotherapy can be effective in treating ovarian cancer that has spread beyond the ovaries. However, the same drugs that kill cancer cells may also damage healthy cells, leading to side effects.

Chemotherapy is usually given in cycles. Periods of chemotherapy treatment are alternated with rest periods when no chemotherapy is given. Most women with ovarian cancer receive chemotherapy for about 6 months (usually 6 cycles) following up front debulking or staging surgery. If neoadjuvant chemotherapy is utilized to help shrink more the cancer areas, 3-4 cycles of chemotherapy is given before a more extensive cytoreductive (debulking) surgery and the remaining cycles of chemotherapy are given after surgery. In some individual cases, it may be appropriate to continue chemotherapy for a longer period of time or for additional cycles.

Other ways to deliver chemotherapy are in the abdominal or peritoneal cavity, called intraperitoneal (IP) chemotherapy. With IP chemotherapy, chemotherapy medications are injected directly into the abdominal cavity in hopes of delivering a large dose directly to the tumor location. Usually, some of the chemotherapy is administered into the abdomen and some is still administered in the vein.

Your surgeon may talk to you about placing a special catheter in your abdomen at the time of your operation if he/she feels that you could benefit from IP chemotherapy. It is important for you to talk with your team about the pros and cons of this approach.

Another type of intraperitoneal therapy is heated IP chemotherapy (HIPEC). During a HIPEC procedure, a chemotherapy drug is heated to a temperature higher than normal body temperature and is circulated at that temperature within the abdomen during surgery. This may be offered in the setting of an interval debulking surgery. Side effects and recovery after HIPEC may be more extensive and pros and cons of this approach should also be carefully discussed. HIPEC should only be performed in select centers with trained teams. While initial clinical trials showed some benefit in select patients, studies are still ongoing to see if this is beneficial for more patients.

## Side effects of chemotherapy

Each person responds to chemotherapy differently. Some people may have very few side effects while others experience several. Most side effects are temporary.

They include:

- Nausea
- Loss of appetite
- Mouth sores
- Increased chance of infection
- Bleeding or bruising easily
- Vomiting
- Hair loss
- Fatigue
- Neuropathy (weakness, numbness, and pain from nerve damage)
- "Chemo brain" (memory lapses, problems with concentration)

## Maintenance therapy

There are many new agents being tested in ovarian cancer that work through new mechanisms and target different pathways that cancer cells need to grow, maintain themselves or spread. These diverse groups of medications are called targeted therapies. Some can be used for initial treatment with standard chemotherapy or as maintenance therapy to reduce the risk of cancer progressing or recurring. Studies of maintenance therapy mostly apply to epithelial ovarian cancers.

Many of these new agents are being investigated in clinical trials. Because these drugs block pathways that are more active in tumor cells, they may not be as damaging to normal cells.

Sometimes these targeted therapies are combined with chemotherapy to try to make the chemotherapy more effective. Targeted therapy drugs have their own unique side effects, which will be discussed by your team.

## Bevacizumab

Bevacizumab is a targeted therapy that blocks new blood vessel formation. It may be given in addition to chemotherapy and as a maintenance therapy after chemotherapy has been completed. It is important to know that bevacizumab can interfere with healing after surgery or other procedures. Because of this, it is usually not given within four to six weeks before a surgery or within four to six weeks after a surgery. Bevacizumab may also cause new or worsening high blood pressure, blood clots, and other side effects. Your treatment team will talk with you about whether bevacizumab is recommended and what side effects to watch for.

## PARP inhibitors

Another class of drugs that can be used for initial treatment of ovarian cancer or for recurrent disease are

drugs called PARP inhibitors. These drugs affect how your cells maintain themselves. There are three that are approved for ovarian cancer: olaparib, niraparib, and rucaparib. PARP inhibitors may be particularly effective for patients with *BRCA* mutations or mutations in other pathways that affect DNA repair (HRD). All three are taken by mouth on a continuous basis. PARP inhibitors are approved for use to maintain the response you may achieve with surgery and chemotherapy for your newly diagnosed ovarian cancer; you may take either olaparib or niraparib for up to two to three years, as long as your cancer stays away. Some women who received bevacizumab during their initial chemotherapy may go on to receive the combination of bevacizumab and olaparib for their maintenance therapy.

## Radiation therapy

Radiation therapy (also called radiotherapy) uses high-energy x-rays, or other types of radiation, to kill cancer cells or stop them from growing in a specific localized area. Radiation therapy is not usually part of the first treatment plan for women with ovarian cancer, but may be used in select cases if the cancer returns. Side effects of radiation and expectations should be discussed with your cancer care team as these will depend on where in the body the radiation will be applied.

## Hormone therapy

A few types of ovarian cancer need hormones like estrogen to grow. In these cases, hormone inhibition or blocking therapy may be a treatment option. Hormone blocking therapy removes female hormones or blocks their action as a way of preventing ovarian cancer cells from getting or using the hormones they may need to grow. Hormone inhibition therapy is usually taken as a pill but can be given as a shot. Sometimes hormone blocking therapies are called anti-estrogen therapy. A common class of these medications also used in breast cancer include aromatase inhibitors or tamoxifen.

## Side effects of hormone inhibition therapy

The side effects depend on the type of hormones being used. Some side effects of hormone therapies can be changes in appetite, vaginal symptoms, muscle or joint pains or hot flashes.

## Immunotherapy

Treatments that engage the patient's own immune system in fighting cancer are called immunotherapy. Some ovarian cancers have molecular changes that make them more likely to respond favorably to immunotherapy. Immunotherapy can be considered as an option if ovarian cancer recurs, although it is only recommended if the ovarian cancer tumors express the immunotherapy target or has molecular changes that suggest the cancer will respond well to immunotherapy. This is usually determined by testing the cancer tissue for molecular changes. Trials are ongoing but currently studies have shown limited benefit for immunotherapy in most patients with ovarian cancer.

## Genetic Testing

The importance of genetic testing in ovarian cancer  
Familial breast-ovarian cancer syndrome is an inherited condition that causes 15–20% of all ovarian cancers and

5–10% of all breast cancers. The association is common enough that it is now recommended that all women with epithelial ovarian cancer undergo genetic testing for an inherited condition.

Panels of genes including the more commonly known *BRCA1* and *BRCA2* genes can be tested using a blood sample or a scraping from the inside of the mouth. The decision to undergo genetic testing and the interpretation of results is recommended to be aided by consultation with a genetic counselor.

Importantly, all genes that increase the risk of ovarian cancer can be passed to both daughters and sons. Inheritance of *BRCA1* mutations is associated with increased risks of breast cancer and ovarian cancer, predominantly. Inheritance of *BRCA2* mutations is associated with increased risks of breast cancer and ovarian cancer, but also cancers that may also affect men, including male breast cancer, melanoma, prostate cancer, and other risks. In female family members diagnosed with an inherited gene that increases ovarian cancer risk, there are medical and surgical interventions that can decrease their risks of developing ovarian and breast cancers. Enhanced cancer screening tests may be recommended for both female and male family members found to have genes that increase their risks.



# Importance of participation in clinical trials

There are many ongoing clinical trials studying new and better ways to treat ovarian cancer. Many treatment options are available today because women diagnosed with ovarian cancer were willing to participate in clinical trials. Clinical trials are designed to test some of the newest and most promising treatments for ovarian cancer. The Foundation for Women's Cancer partners with NRG Oncology (formerly Gynecologic Oncology Group), part of the National Cancer Institute's National Clinical Trials Network, and others to make information about current clinical trials available. For more information about clinical trials available for enrollment, visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov).

## Tumor genetic testing

In addition to a blood test that can reveal information about familial or hereditary cancers, ovarian cancer tumors can have local mutations and changes in the genes. Testing of the genes in the tumor itself is sometimes ordered to be able to understand mutations in the tumor that may direct treatment options. This can be performed on tumor samples from surgery or biopsy.

## Follow up after treatment

In general, women are followed up with exams (including a pelvic exam) every three to four months for three years, and then every six months. In addition, CA 125 and imaging studies such as x-rays, CT scans, or MRIs may be periodically performed, especially if you have any new pain or symptoms.

## Recurrent disease

Recurrences are often diagnosed when the CA 125 level begins to rise, or new masses are found on imaging studies or by examination. A biopsy may be required to be certain a lesion is a recurrent tumor.

There are several options for treatment if your ovarian cancer recurs. These include repeat surgery, re-treatment with the same chemotherapy given initially, treatment with a different type of agent (chemotherapy, hormonal, immunotherapy, or targeted therapy), and sometimes radiation or a combination of approaches. As each recurrence will be unique, it is important to discuss your individual situation with your team. It is also important to investigate whether there is a clinical trial that is appropriate for you. Don't be afraid to seek a second opinion.



# Living with cancer therapy

The experience of being diagnosed with ovarian cancer and undergoing cancer treatment can naturally lead to physical, emotional, and psycho-social changes that may affect your life in many ways. There are common side effects discussed here although each person's experience with a cancer diagnosis is unique. Being aware of the possible treatment side effects may help you work with your cancer care team to anticipate and plan ways to cope and manage any symptoms or concerns.

## Fatigue

Regardless of the treatment prescribed, you are likely to experience fatigue, frequent medical appointments, and times when you do not feel well enough to take care of tasks at home. You may need to rely on family and friends to help with some of the things you usually do at times. You may want to consider hiring someone for help with chores until you feel well enough to manage again.

If you know that you will not have support at home, talk frankly with your health care team as early as possible so that alternatives can be explored. Since a nourishing diet is important, be sure to ask for help, if needed, in maintaining healthy meal and snack choices in your home.

Discuss the fatigue you are experiencing with your doctor to help with diagnosis and management options. Blood tests may help to rule out anemia (low red blood cell counts) or thyroid issues as treatable causes of fatigue. Be sure that your blood count is checked to rule out anemia as a treatable cause of fatigue. Ironically, engaging in physical activity has been shown to improve fatigue in some patients.

## Facing the world

The effects of cancer and your cancer treatment may alter your appearance. You may appear fatigued, pale, and slow-moving, and you may have to face temporary hair loss. You may feel self-conscious because of these changes. It might help to imagine how you might feel if you saw a friend or sister looking as you do. Remember that many people are loving you rather than judging you as they notice these changes.

## Work accommodations

You may need to be away from work quite a bit during the first month or two of your treatment. Talk with your supervisors at work and with your health care team to set up a realistic plan for work absences and return to work. Remember to tell your work supervisor that any plan must be flexible because your needs may change as treatment progresses. The Family Medical Leave Act (FMLA) offers certain protections for workers and family members who must be away from work for health reasons.

## Family, friendships, and fun

No matter what type of treatment you have for your ovarian cancer, you may experience side effects that could affect how you feel about joining in social events with friends and family. Talk to your health care team if special events are coming up, such as a wedding or graduation. It may be possible to adjust the timing of your treatments so that you feel as well as possible for these special days. Don't hesitate to plan activities that you enjoy. You may

have to cancel an occasion or leave a little early, but the good times will help you to find strength for the hard days. It is often difficult for young children to understand what you are going through. Counselors are available to help you answer questions and to help your children cope. It is also a good idea to ask family and friends to help you keep your children's normal routine.

## Driving

For many people, driving is an almost indispensable part of adult life. You should not drive if you are taking medications that cause drowsiness, such as narcotic pain relievers and some nausea medications. Most patients can start driving again within a few weeks of surgery, and usually patients can drive most days during chemotherapy and radiation therapy. Be sure to ask your health care team about driving.

## Exercise

During treatment, you may find that even walking the stairs to your bedroom are a challenge, even if you have worked hard during your adult life to keep fit. Discuss with your provider how to rebuild your physical activity levels. Recognize that some days you may feel able to challenge the world but other days, you do not. That is to be expected. If you've had surgery, ask your doctor for specific guidelines about exercise. During chemotherapy or radiation therapy, adjust your exercise according to how you feel. Consultation with physical therapists experienced with working with patients with cancer can be a good resource after surgery or during/after chemotherapy. You should avoid overexerting or dehydrating yourself. Make sure you drink a lot of fluids. Over the weeks and months after you finish cancer treatment, you can build back toward your previous level of fitness and define your personal new normal.



# Sexuality & intimacy

Some treatments for ovarian cancer can cause side effects that may change the way you feel about your body or make it more difficult to enjoy intimate or sexual relationships. Side effects you experience depend on many factors including age, menopausal status and your specific surgical and medical treatments. You may experience some or none at all. Being aware of the possible side effects may help you anticipate them and learn ways to cope.

## Possible side effects include:

**Hair loss.** A common side effect of chemotherapy, hair loss is usually temporary. Still, it can be difficult to accept. Part of the chemotherapy regimen used when a woman is first diagnosed with ovarian cancer causes hair loss in nearly all women who receive it. Hair loss usually starts about two to three weeks after the first dose of that chemotherapy. Some chemotherapy drugs can make hair loss occur abruptly. If you experience hair loss, you may choose to wear wigs, scarves, or other head wear. Also, consider talking to your treatment team about the option of using a cooling cap, a medical device that cools the scalp during chemotherapy administration. This has been shown to decrease hair loss by about 50% in clinical studies. Many cancer centers and support centers can help with these types of resources.

**Vaginal and pelvic changes.** Some forms of treatment, such as surgical removal of your ovaries, especially if done before you experienced menopause, will cause a lack of estrogen which can affect vaginal health. This can cause atrophy or thinning of the vaginal tissue with decreased blood flow and decreased flexibility or narrowing. This can cause symptoms of dryness, discomfort and even pain with intercourse. Surgery and radiation therapy can also lead to these changes and may cause pelvic pain, or dryness, shortening, and narrowing of the vagina. These changes can make some sexual activity uncomfortable. Talking to your providers about this topic is important as they may recommend resources and treatment options. Symptoms can often be improved with over the counter lubricants and

vaginal moisturizers, or vaginal dilators. Physical therapists who specialize in vaginal and pelvic health may also be an important resource to consider.

**Reduced sexual desire.** After an ovarian cancer diagnosis, many factors can contribute to the lack of desire related to sexual activity. The loss of your ovarian hormones, effects of surgery, chemotherapy or other new medications, or the stress and fatigue you may experience during cancer treatment or after may cause you to lose interest for a period of time. Depression and anxiety can also contribute to these feelings. A therapist trained specifically in counseling on sexual function management may be a helpful member of your overall cancer care team.

## Tips for coping

Talk with your treatment team. They can provide advice based on your individual situation, so it is very important that you talk honestly with them. You may want to ask:

- How will my treatment affect my sexuality?
- Will these effects be temporary?
- Are there other treatment options that might lessen these effects?
- Do you have suggestions about how I can deal with the effects of treatment on my sexuality?

**Communicate with your partner.** Cancer can strain both partners in a relationship. Talking about the sexual and emotional effects cancer has on your relationship can be difficult. But you may find it easier to work through the challenges if you talk about them. Be prepared to share your own feelings and to listen to what your partner has to say.

**Shift your focus to intimacy.** Sexual intercourse is only one part of intimacy. You may find that touching, kissing, and cuddling are equally fulfilling.

**Be patient with yourself.** Understand that a return to a sexual relationship may take time. Your treatment team can tell you if and how long you should wait to have sex after treatment. It may be longer before you feel emotionally ready. Give yourself the time you need.

**Keep an open mind.** Having an open mind and a sense of humor about ways to improve your sexuality may help you and your partner find what works best for you.





# Hopeful Messages

Nurture yourself as you go through this journey.

Be open to help, caring, and support.

Finding your new normal may take time, be patient.

Your treatment team can guide you through the difficulties that you will face if they know what is troubling you.

Talk openly about the things that bother you.

Give yourself the time you need.

**Nurture hope.** It's up to you to take charge of your reaction even as you face the unknown of cancer. Hope helps you see the positive aspects of life.

If you have inner spiritual beliefs, reach out to your religious community to give you additional support to face each day and LIVE.

**Seek support.** There are many resources available to help you deal with the physical, sexual, or emotional issues you may have as a result of cancer and its treatment. Specially trained counselors can help you deal with the impact of cancer on your life.

Support groups both in person or online through trusted organizations are another good resource. People who are facing a situation similar to yours can come together to share their experiences and give one another advice and emotional support. Local cancer center often offer other group activities related to health and well being specifically targeting patients with cancer. To find support services in your area, talk with a member of your treatment team or contact the resources on the next page.

Advance medical directives can be a helpful tool for clarifying your medical care wishes. We encourage both patients and families to complete one. Your health care team is available for guidance on this matter.

# Facts to share

Only 15% of all ovarian cancer cases are detected at the earliest, most curable stage.

One in 71 women will develop ovarian cancer in her lifetime.

Ovarian cancer is the fifth leading cause of cancer death in women in the US.

## Risk factors

- Risk increases with age, especially around the time of menopause.
- Family history of ovarian cancer, fallopian tube cancer, primary peritoneal cancer, or premenopausal breast cancer, or a personal history of premenopausal breast cancer.
- Infertility and not bearing children are risk factors, while pregnancy and the use of birth control pills decrease risk.
- Family history of both colon and endometrial cancers; any male family member with breast cancer.
- Ashkenazi Jewish heritage.

## Symptoms

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

These symptoms are particularly concerning if they occur almost daily for a few weeks or more. If this happens to you, see a doctor, preferably a gynecologist, and specifically ask about the possibility of ovarian cancer as a cause of your symptoms. *If ovarian cancer is suspected or diagnosed, seek care first from a gynecologic oncologist.*





# How you can help

- Raise awareness about gynecologic cancers.
- Donate to the Foundation for Women's Cancer online.
- Host your own fundraising event or partner with the Foundation.
- Give a Matching Gift through your employer to the Foundation.
- Give gifts of stock or securities to the Foundation.
- Designate a planned gift to the Foundation.

The Foundation for Women's Cancer offers many resources for patients, advocates and the general public, including Survivor Courses around the U.S., webinars and an online education series.

To make a gift or for additional information, please email the Foundation at [info@foundationforwomenscancer.org](mailto:info@foundationforwomenscancer.org) or call 312.578.1439.

**Donate & learn more**

**[Foundationforwomenscancer.org](https://www.foundationforwomenscancer.org)**



The Foundation for Women's Cancer (FWC) is a 501(c)3 nonprofit organization dedicated to increasing research, education and awareness about gynecologic cancer risk, prevention, early detection and optimal treatment.

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