



RESOURCE GUIDE FOR THOSE  
**NEWLY DIAGNOSED**





## 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 countless local community partners to raise awareness about ovarian cancer. The NOCC is an influential national advocate for patients, survivors, caregivers, and their families struggling with ovarian cancer 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 everyone 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.

**For more information about the NOCC, visit [ovarian.org](https://ovarian.org) or call 1-888-OVARIAN (1-888-682-7426).**

## The Journey Begins

A diagnosis of ovarian cancer, without a doubt, may be one of the most stressful things you’ll ever experience. You and your loved ones are suddenly thrust into a world of medical tests, surgical procedures, and treatments. You may feel overwhelmed, anxious, and scared.

One thing you should know is that you are not alone. The National Ovarian Cancer Coalition (NOCC) is here to support you, your family, and your caregivers throughout your journey.

We are here to provide you with information, compassion, and encouragement. This guide empowers you with the knowledge to take care of your health. The guide includes five sections:

- Understanding Ovarian Cancer
- Ovarian Cancer Treatment
- Managing Your Treatment and Coping with Side Effects
- Resources
- Glossary of Cancer Terms

Receiving a cancer diagnosis is life-changing; however, it’s important to know many with ovarian cancer do gradually go on to live full and rewarding lives despite their cancer diagnosis.

Remember, since treatments and research constantly evolve, check in with us often for the latest updates. You can always visit our website, [ovarian.org](https://ovarian.org), call 1-888-OVARIAN, or contact your local NOCC market for more information.

### Follow Us on Social!



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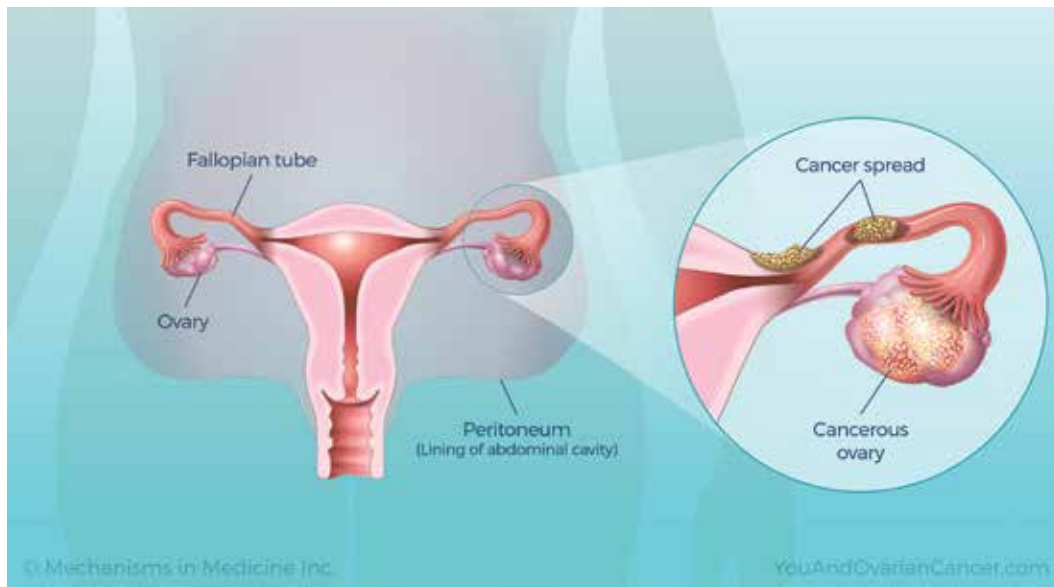
# CHAPTER 1

## UNDERSTANDING OVARIAN CANCER

### What is Ovarian Cancer?

Ovarian cancer is a disease in which cancer cells are found in the ovaries, two small organs located in the lower abdomen. They are about the size of an almond, with one on each side of the uterus (the hollow organ where a fetus grows). The ovaries release an **egg** (ovum) every month during a menstrual cycle. The egg travels through the fallopian tubes into the uterus and can become fertilized. The ovaries are also the main source of the female reproductive hormones estrogen and progesterone. These hormones control sexual development and regulate the menstrual cycle. During menopause, the ovaries stop releasing eggs and produce fewer hormones.

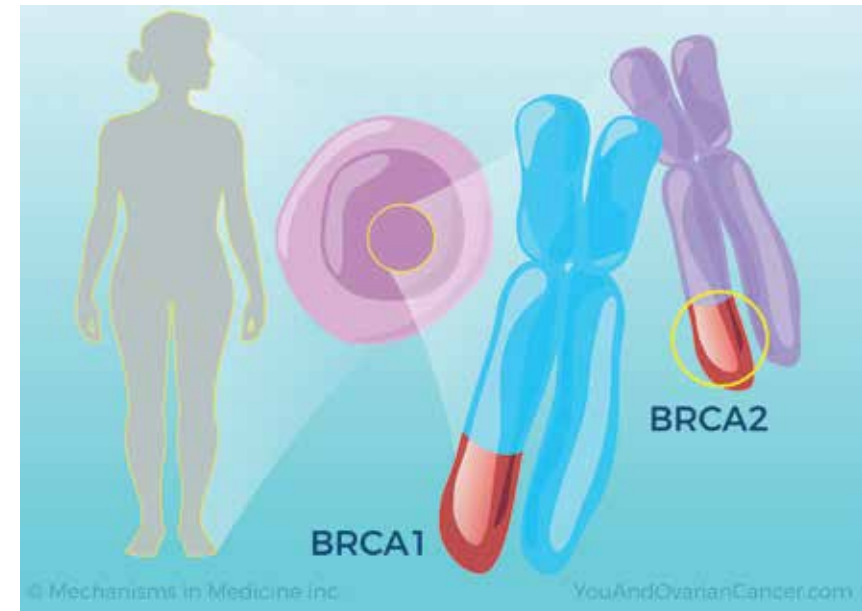
The cells in your body usually grow and divide in a very controlled process. Sometimes, this process goes wrong, and your body makes too many new cells. These extra cells can grow out of control and form a mass called a **tumor**. Tumors may be benign (not cancer) or malignant (cancer). Ovarian cancer cells can travel to other parts of the body, where they begin to grow again. The cells can spread to nearby organs such as the fallopian tubes or the other ovary. They can also spread to other organs in your body. When cancer cells spread, this process is called **metastasis**. Even if it spreads to another organ, it is still ovarian cancer and is treated as such.



Source: [www.YouAndOvarianCancer.com](http://www.YouAndOvarianCancer.com) ©Mechanisms in Medicine Inc. All rights reserved.

### What causes ovarian cancer?

Unfortunately, we do not know what causes ovarian cancer. The risk of ovarian cancer increases as you age and is more common in those over 60. However, it can develop at any age. A family history of ovarian, breast, or colorectal cancer can increase your risk of ovarian cancer. Anyone with ovaries is at risk for ovarian cancer, but risk factors don't tell you everything. Many people who get ovarian cancer do not have any known risk factors. Even if you have a risk factor, it's still hard to know what part it may have played in the development of your cancer.



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### Genetics and genetic counseling

Most cancers occur randomly or by chance, but sometimes a person carries a change (or mutation) in a gene that can increase their chances of developing cancer. This is called an inherited cancer risk. Changes in the **BRCA1** (BReast CAncer gene 1) or **BRCA2** (BReast CAncer gene 2) genes can increase your risk of developing ovarian and breast cancer. Those with changes in the BRCA1 gene have a lifetime risk of 35-70 percent developing ovarian cancer. Individuals with changes to the BRCA2 gene have a 10-30 percent lifetime risk. Without a mutation or change, the risk of ovarian cancer is less than 2 percent. Other genetic changes can also increase the risk of ovarian and breast cancer. Genetic testing is an active area of research. If you had testing done more than five years ago, your healthcare team might recommend testing again with newer tests. If your family health history changes, such as if additional family members develop cancer, your team also might recommend additional genetic testing.

Before having genetic testing, you should talk with a genetic counselor. They help you decide how to use the results of your tests, including who to tell, who else should be tested, and what treatment or risk reduction options are right for you.

If you have children, consider genetic testing since you could pass a gene mutation to them.

Men can also have and pass the BRCA1 and BRCA2 gene mutations to their children. Remember that not everyone who inherits a BRCA gene mutation will develop cancer.

Some experts recommend genetic testing if you're of Ashkenazi Jewish descent and have a first-degree family member (parent, sibling, or child) or two second-degree relatives (grandparent, aunt, or niece) on the same side of the family with these cancers. Even if you are not Jewish, the test is recommended if there's a history of these diseases, fallopian tube, or peritoneal cancer in your family.

Not all gene mutations are inherited from parents. Some develop on their own over time. These mutations include TP53, PTEN, and PALB2, among others.

**For more information on genetic testing or help finding a healthcare professional trained in genetics, contact the National Cancer Institute's Cancer Information Service (CIS): 1-800-4-CANCER (1-800-422-6237)**

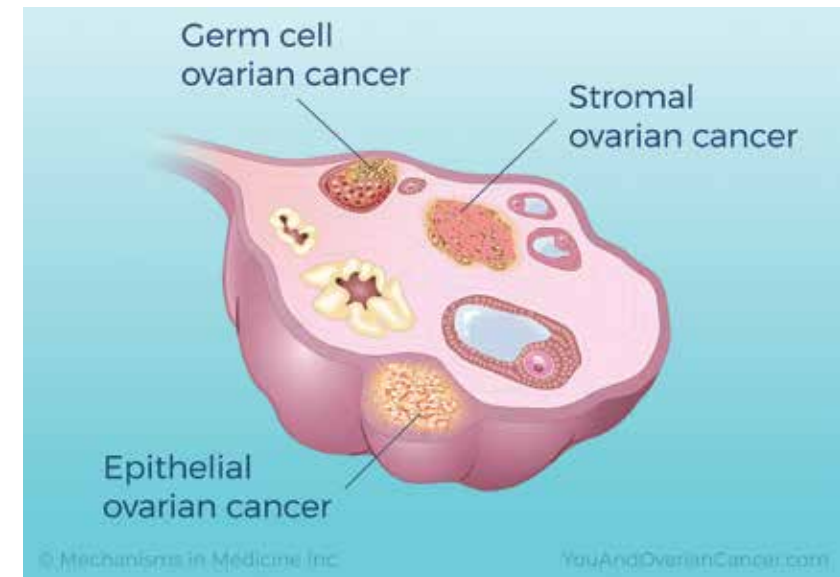
## Types of ovarian tumors

There are many types of ovarian cancer. The three most common types of ovarian cancer are epithelial, germ cell, and stromal tumors.

### Epithelial tumors

About 90 percent of ovarian cancers are epithelial tumors. These tumors start in the **epithelium**, which is the tissue that covers the outside surface of the ovary. The chance of getting this type of cancer increases as you age, especially for people over 60. However, it can happen at any age. Most of these cancers are found at an advanced stage when the disease is more serious. There are many subtypes of epithelial ovarian cancers:

- Serous carcinomas (most common)
- Endometrioid carcinoma (less common)
- Clear cell carcinoma (less common)
- Mucinous carcinoma (less common)



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### Germ cell tumors

This type of ovarian cancer starts in the **germ cells**, which produce individual eggs. Germ cell tumors are rare and mainly affect teenagers and those in their 20s. Many germ cell tumors are not cancer. There are many subtypes of germ cell tumors:

- Immature teratomas
- Dysgerminomas
- Endodermal sinus tumors (yolk sac tumor)
- Choriocarcinomas
- Embryonal carcinoma

### Sex cord stromal tumors

These rare tumors develop in the connective tissue that holds the ovary together. The hormones estrogen and progesterone are made in the **stromal cells**. These tumors typically occur in those over the age of 50. There are many subtypes of these tumors:

- Granulosa cell tumor
- Sertoli cell tumor
- Sertoli-Leydig cell tumor

### Other rare ovarian cancers

Small-cell ovarian cancer is a very rare, aggressive type of cancer. Unfortunately, little is known about this type of ovarian cancer, and there are no specific treatment guidelines.

## Stages of ovarian cancer

Once you are diagnosed with ovarian cancer, your surgeon determines the stage of the cancer based on how far it has spread from the ovaries. Like most cancers, ovarian cancer has four main stages.

### Stage I

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In **Stage I**, cancer is in one or both ovaries and may also be on the outer surface of the ovaries or in fluids in the abdomen. It is divided into three substages – A, B, and C:

**Stage IA** – Cancer is in one ovary or fallopian tube. There is no cancer on the outside surface of the ovary. No cancer cells are found in ascites or washings.

**Stage IB** – Cancer is in both ovaries or fallopian tubes. The capsules are intact, and there is no cancer on the outside surface of the ovaries. No cancer cells are found in ascites or washings.

**Stage IC:** Cancer is in one or both ovaries, and one or more of the following has also happened:

- **Stage IC1:** The tumor ruptures while it is being removed surgically, called intraoperative surgical spill.
- **Stage IC2:** The tumor wall is ruptured before surgery, or there is cancer on the surface of the ovary or fallopian tube.
- **Stage IC3:** Cancer cells are found in fluid buildup in the abdominal cavity, called ascites, or in the fluid samples from the peritoneal cavity taken during surgery.

### Stage II

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In **Stage II**, cancer has spread to the fallopian tubes or other organs in the pelvis. It is divided into two substages: A and B.

**Stage IIA:** The cancer has spread to the uterus and/or fallopian tubes and/or the ovaries.

**Stage IIB:** The cancer has spread to other tissues within the pelvis, such as the bladder, colon, rectum, or the peritoneum within the pelvis. The peritoneum is the tissue that lines the abdominal cavity and surrounds the abdominal organs.

### Stage III

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**Stage III** means your cancer has spread outside the pelvis into the lining of the abdomen or the lymph nodes (small glands in your body) in your upper abdomen, groin, or beyond the uterus.

**Stage IIIA1:** Cancer has spread outside of the pelvis but only to lymph nodes in the back portion of the abdomen.

**Stage IIIA2:** Cancer has spread to the tissue lining the abdomen (only visible by microscope) and/or the lymph nodes in the back of the abdomen.

**Stage IIIB:** Cancer has spread to the tissue lining the abdomen (visible without a microscope) and is 2 cm or smaller. It may have also spread to the lymph nodes in the back of the abdomen.

**Stage IIIC:** Cancer has spread to the tissue lining the abdomen (visible without a microscope) and is larger than 2 cm. It may have also spread to the lymph nodes in the back of the abdomen or to the outer surface of the liver or spleen.

### Stage IV

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**Stage IV** is the most advanced stage of ovarian cancer. The cancer is growing in one or both ovaries and has spread to other organs like the liver and lungs.

**Stage IVA:** Cancer cells are found in the fluid around the lungs, but it has not spread outside the abdomen.

**Stage IVB:** Cancer has spread to the inside of the liver or spleen, distant lymph nodes, or other organs outside of the abdomen.

#### CHRISTA

*“Despite my shock, fear, and anxiety of my recent cancer diagnosis, I immediately sprang into action and became my own best advocate. The best advice I could offer someone facing an illness is to stay positive no matter how much it tears you down, fight for the life you deserve, and please be proactive because no one at any age, class, or race is invincible to cancer, disease, and illness.”*

## Your Healthcare Team

You will meet many different healthcare professionals in many departments while you're being treated for ovarian cancer. You will need both good communication skills and a lot of patience. Your healthcare team may include the following:

- Gynecologic oncologist
- Oncology nurses
- Nutritionist
- Social worker
- Office or clinic receptionist
- Psychologist
- Nurse practitioner
- Physical therapist
- Patient navigator

## Finding a gynecologic oncologist

If you need surgery for a suspicious ovarian mass or have already had surgery, it's a good idea to seek the opinion of a gynecologic oncologist. A gynecologic oncologist is a doctor who specializes in diagnosing and treating cancer of the reproductive organs.

In the last 20 years, research has shown that surgery by a gynecologic oncologist is a top factor in increasing ovarian cancer survival rates and decreasing rates of recurrence. Gynecologic oncologists are skilled surgeons trained in prescribing appropriate treatment and care for cancers of the female reproductive organs.

Of course, location and insurance coverage may determine what kind of oncologist will treat you. There are approximately 1,500 board-certified gynecologic oncologists in the U.S. Those who do not live near a gynecologic oncologist or whose insurance company does not have one in their network should at least seek a second opinion from one. Other types of doctors who help treat those with ovarian cancer include gynecologists and medical oncologists.

Your first step in finding a gynecologic oncologist is to ask your physician for the names of any gynecologic oncologists in your community. You can also find one by searching the Foundation for Women's Cancer national list of gynecologic oncologists at [foundationforwomenscancer.org](http://foundationforwomenscancer.org). Also, contact your insurance provider. Ask what oncologists are in the network and if any are gynecologic oncologists.

## Questions to consider when choosing your doctor

- Is your doctor a gynecologic oncologist?
- Are they experienced in treating your kind of ovarian cancer?
- Do they accept your insurance?
- Do you find it easy to communicate freely with them?
- Were you comfortable with the response you received when contacting the office?
- Does the doctor have a good reputation among other doctors and patients?
- Will they be in charge of your treatment, or will a team be involved? Who is on that team?
- Does the doctor (or someone from the office) return your calls quickly?

### Some questions to ask your doctor

- What type of ovarian cancer do I have?
- What stage is my cancer, and what does that mean?
- Has all my cancer been removed?
- What tests were done on my tumor to determine treatment?
- Do you recommend genetic testing that may help inform my treatment options and provide valuable information to my family?
- What are my treatment options?  
If chemotherapy, what chemotherapy drugs do you recommend?
- How many treatments will I need?  
How frequent will they be?
- Does my insurance plan cover my treatments?
- What side effects will I have from chemo? Is there anything I can do to alleviate them?
- Should I continue to take prescription medications for other medical conditions?
- Should my diet change while I undergo treatment?
- Will I be able to work? Care for my family?
- Will I need additional surgery?
- Can you recommend a counselor for me to talk to?



## Getting a second opinion

Once your doctor tells you your diagnosis and treatment plan, you may want another doctor's advice before you begin treatment, known as getting a second opinion. Getting a second opinion is a commonly accepted practice. Yet, many people do not seek one because they fear they will offend their current physician or don't have the energy to find and see another doctor.

Getting a second opinion may be beneficial. Ensure you get a copy of all test results, lab and pathology reports, and all records regarding your conditions. If a second opinion confirms your original doctor's diagnosis, you will only feel more comfortable about your treatment decisions. If the new opinion is different, it will inspire you to ask more questions and allow you to make a better-informed decision about your course of treatment.

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### Questions to ask when getting a second opinion

- Do you agree with the original diagnosis?
- What treatment plan would you recommend?
- Why is your suggestion different from the first doctor's plan?

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### Communicating with your healthcare team

After you find out that you have ovarian cancer, you will most likely have many questions, worries, and fears. You may worry about changes in your body, the effect your illness will have on your family and friends, and whether you will survive the disease or treatment. Do not hesitate to talk with your healthcare team. They are there to help you. Many find it helpful to consult with a psychotherapist to help them get through the difficult early period after diagnosis. Your healthcare team may be able to refer you to someone who specializes in working with people who have cancer.

Also, ask your healthcare team what hospital services are available to you. There may be support groups, financial or transportation assistance, information about nutrition and exercise, or other programs. But the information might only be offered if you ask for it. You are your own best advocate. Communicate openly and frequently with your team, family, and friends.



### Getting the most out of your doctor visits

In reality, even the most caring and communicative doctors have hectic schedules and often have limited time to spend with their patients during each visit. You can make the most effective use of your medical appointments by preparing in advance.

- Prepare questions in advance. Write down your questions for your doctor before each visit and bring them to your appointment. Don't be shy. Every question you have is important.
- Ask the most important questions first. You may not get through your whole list, but at least you'll get the most important ones answered.
- Bring a second pair of ears and a notepad. Concentrating and remembering information when you visit the doctor can be difficult. Consider taking a family member or friend to your appointments to help you write down what the doctor says. You also might find it helpful to record the conversation. Since not all doctors are comfortable with this, ask if it's okay first.
- Request easier explanations. If the doctor answers in technical language you do not understand, ask them to rephrase what's being said in a way you can understand.
- Be your own advocate. Don't feel like you are "taking up time" or asking too many questions. This is your appointment, your time to consult with your physician. Be respectful of your doctor's schedule, but meet your needs.
- Keep track of your health between appointments. Tell the doctor about any notable changes in your health or the way you feel.



## CHAPTER 2

# OVARIAN CANCER TREATMENT

Treatment for ovarian cancer is not the same for everyone. Your doctor will develop a personal treatment plan for you. Your treatment plan depends on the kind of tumor you have and the stage of the cancer. It also depends on your age, desire to have children naturally, and your overall health. Unfortunately, most individuals diagnosed with ovarian cancer are diagnosed when the disease is more advanced, which makes them more challenging to treat.

As science progresses, ovarian cancer treatment options expand, and therapies advance. Treatments for ovarian cancer include surgery, chemotherapy, targeted therapy, immunotherapy, hormone therapy, and radiation.

## Surgery

Most ovarian cancers are treated with surgery and should be performed by a qualified gynecologic oncologist. The type of surgery you have depends on where the tumor is and how much the cancer has spread. In most cases, there are two goals for surgery: staging and debulking.

The first goal of ovarian cancer surgery is to stage the cancer - to see if and how far the cancer may have spread to other places in the body. Staging may involve removing the uterus (hysterectomy), as well as both ovaries and fallopian tubes (bilateral salpingo-oophorectomy). The omentum, a layer of fatty tissue that covers the abdominal contents, may also be removed (omentectomy).

Debulking surgery aims to remove as much tumor tissue as possible while preserving the surrounding organs. During debulking surgery, other organs may also need to be removed. For early-stage tumors, doctors can sometimes remove the cancer without taking out both the ovaries and the uterus. If both ovaries and/or the uterus are taken out, a woman won't be able to get pregnant. This also causes menopause, which brings symptoms like hot flashes, night sweats, changes in sex drive, and vaginal dryness.

## Chemotherapy

Chemotherapy (often referred to as “chemo”) uses drugs that travel through the bloodstream to destroy cancer cells or stop them from growing both in and outside the ovaries. It is often used as a follow-up to surgery. However, chemotherapy is sometimes used before surgery (called neoadjuvant chemotherapy) to shrink the tumor and make it easier to remove all of the cancer.

Before you begin chemotherapy, it is important to understand how chemotherapy works. Chemotherapy is used to stop fast-growing cancer cells, shrink tumors before surgery or radiation, and help ease symptoms in later stages of cancer.

Chemotherapy is usually provided at a cancer center, hospital, or doctor's office. You may be given chemotherapy in pill form or receive it through an IV, which involves a needle inserted into a vein. This process is often referred to as a chemo infusion. During chemo infusions, the drugs enter your body through a thin tube called a catheter placed in a vein, artery, body cavity, or specific body part. In most cases, chemotherapy is given through a port. A port is a small device implanted under the skin, usually in the chest area. It looks like a small disc or button with a thin tube attached to it. The tube is inserted into a large vein, usually in the chest or neck. Ports make it easier and more comfortable for patients to receive chemotherapy because they don't have to get poked with needles in their arms every time they need treatment. Plus, it helps protect their veins from damage.

In some cases, chemotherapy may also be injected through a catheter (thin tube) directly into the abdominal cavity. This is called **intraperitoneal (IP) chemotherapy**.

Chemotherapy is given in regular cycles on one or more days. How often you have chemo and how long it lasts depends on your cancer type, treatment goals, the drugs used, and how your body reacts. Some drugs are given weekly, several days in a row, or even just once a month, depending on the type of cancer you have and the type of chemotherapy you are receiving. Your cancer care team can tell you how many cycles are planned and how long they expect your treatment to last.



## MIRNA

*“Being told you have cancer is never something you want to hear, but I had to face that reality when diagnosed with a germ cell tumor. As a physician assistant working in oncology, my journey allowed me to be more empathetic to my patients, and for that, I am very grateful.”*

## Targeted Therapy

Targeted therapies use drugs designed to target cancer cells without harming normal cells. It attacks specific areas in cancer cells, such as gene mutations normal cells do not have. It may be used in combination with other treatments, like chemotherapy. Targeted therapy can slow the growth of advanced epithelial ovarian cancer. An example of a targeted treatment based on tumor testing is **PARP inhibitors**. This class of drugs makes it hard for damaged cancer cells to repair their DNA, which leads to cancer cell death.

## Immunotherapy

Immunotherapy is a treatment that uses your body’s immune system to fight cancer. It trains your immune system to do a better job of finding and killing cancer cells. Immunotherapy also helps your body produce cancer-fighting immune cells.

## Hormone Therapy

Hormone therapy is a treatment that slows or stops the growth of cancers that use hormones to grow. It is usually used to treat ovarian stromal tumors. It is rarely used to treat epithelial cancers.

## Radiation Therapy

Radiotherapy, also known as radiation therapy, uses high-energy X-rays to kill cancer cells and shrink tumors. Although it isn’t commonly used in the treatment of ovarian cancer, it does have a limited role in treating ovarian cancer. Radiation is sometimes used to treat isolated areas of a tumor that are causing pain and other problems and are no longer responsive to chemotherapy.

## Biomarker Testing (Tumor Testing)

**Biomarkers** are protein or genetic changes made by a tumor and found in the blood. Testing the tumor for certain biomarkers can help doctors learn how your cancer behaves. Tumor testing may help predict how fast the cancer is growing and which treatments may work best—such as **targeted treatments** or **immunotherapy drugs**.

There are many types of tumor biomarkers, and each may respond to different treatments.

Ask your doctor about the biomarker testing performed on your tumor. Some of the most common biomarkers and their treatments include:

- BRCA1/BRCA2 mutations - PARP inhibitors such as Lynparza (olaparib)/Rubraca (rucaparib)/Zejula (niraparib)
- HRD (Homologous Recombination Deficiency) - Avastin (bevacizumab)/Lynparza (olaparib)/Zejula® (niraparib)
- MMR/MSI (Mismatch Repair Gene/Microsatellite Instability) - Keytruda (pembrolizumab)
- NTRK fusion - Vitrakvi (larotrectinib)
- TMD (Tumor Mutational Burden) - Keytruda
- FR-alpha (folate receptor-alpha) - Elahere (mirvetuximab soravtansine)
- CA-125 (Cancer antigen 125) - monitors recurrence and response to treatment

Tumor testing can also reveal mutations and biomarkers that could point you toward a clinical trial. Clinical trials are another option for receiving treatment. They are a way for you to benefit from personalized medicine by finding the treatment options best matched to your specific cancer.

### What’s a CA-125 test?

The CA-125 test determines the amount of the protein CA-125 in your blood. CA-125 is present more in ovarian cancer cells than in other cells. CA-125 is an important test but not a screening tool because other health conditions can cause this level to rise. Some ovarian cancers may not produce enough CA-125 levels to cause a positive test. However, the CA-125 helps in monitoring those who are being treated for ovarian cancer. An elevated CA-125 may indicate a recurrence while decreasing levels generally indicate that the therapy has been effective. An HE4 blood test has also been used to monitor recurrent or progressive disease in those with epithelial ovarian cancer.

## Clinical Trials

Clinical trials are research studies designed to improve health, answer scientific questions, and find better ways to prevent, diagnose, or treat cancer. For many with ovarian cancer, investigational treatments may offer new hope. Through participation in these trials, patients may receive access to new therapy options that are unavailable beyond the clinical trial setting.

### What are the phases of clinical trials?

All clinical trials are conducted in phases. Each clinical trial phase has a different purpose.

- In **Phase I** trials, the question is: Is the treatment safe? Researchers test a new drug or treatment in a small group of people (10-80) for the first time to evaluate its safety, determine a safe dosage range, and identify side effects.
- In **Phase II** trials, the question is: Does the treatment work? The new drug or treatment is given to a larger group of people (100-300) to see if it's effective and to evaluate its safety further.
- In **Phase III** trials, the question is: Is the new treatment or drug better than what is currently available? The new drug or treatment is given to large groups of people (1,000-3,000) to confirm its effectiveness and benefits and to monitor possible adverse reactions.
- In **Phase IV** trials, the question is: What else do we need to know? The focus is on long-term effectiveness and side-effect monitoring.

Today, clinical trials are conducted in most hospitals and cancer treatment centers across the U.S. To ensure the reliability of the data and the safety of all participating patients, all clinical trial researchers conduct their studies under the strict guidelines of the FDA.

### Should you participate in a clinical trial?

Whether or not you should join a clinical trial requires a lot of thought and consideration. You should decide in close consultation with your loved ones and your healthcare team. Keep in mind that clinical trials are only open to people who meet very specific medical requirements; every person is not eligible for each clinical trial.

#### Benefits to consider:

- you can be among the first to receive new treatments before they are made available to the public;
- you can obtain expert medical care at leading healthcare facilities during the trial; and
- you can withdraw from a clinical trial at any time. For those experiencing resistant or recurrent ovarian cancer, investigational treatments can offer new hope.

#### Cons to consider:

- the treatments are under investigation and may have unknown side effects;
- the treatment may not be effective for you;
- the study might require more time and attention on your part, including trips to the study site.

It is important to ask questions before deciding to enter a clinical trial. Write down your questions or have a friend take notes when you meet with your doctor and the trial staff.

#### Questions to ask when considering a clinical trial

- What is the purpose of the trial?
- Who is conducting the trial?
- How many patients will be involved?
- What will happen to me if I do or don't participate?
- Where is the trial being conducted?
- How long will the trial last?
- What type of treatments or tests will I have?
- What are the possible benefits and risks to me?
- Does the treatment have side effects?
- Will any hospitalization be involved?
- Will I have any costs? Do I have to pay for any part of the trial?
- Will my insurance cover the rest?
- Will I still be seeing my regular doctor?

### Clinical trial resources: Where do I begin?

Following are some valuable resources that will help you learn more about clinical trials that might be appropriate for you.

#### Clinicaltrials.gov

A service of the National Institutes of Health (NIH), this is a registry of federally and privately supported clinical trials conducted in the U.S. and worldwide.

**CenterWatch**  
888.838.5578  
centerwatch.com

CenterWatch is a clinical trial listing service for ovarian cancer medical research trials actively recruiting patients.

#### EmergingMed emergingmed.com

This site allows you to create a profile that can be matched to clinical trials.

**The Center For Information And Study  
On Clinical Research Participation  
(CISCRP)**  
877-633-4376  
cisrcrp.org

This free service is designed to help people find clinical trials relevant to their medical and healthcare needs.

## CHAPTER 3 MANAGING YOUR TREATMENT AND COPING WITH SIDE EFFECTS

### Managing Treatment

#### Preparing your treatment schedule

After you and your doctor have determined your treatment plan, you will need to work with your healthcare team to figure out the dates and times of your treatment and to determine whether the schedule is flexible.

Communicating with your healthcare team is essential as you plan your treatment schedule. If the team knows your preferences, they can accommodate your needs and requests when possible. Your healthcare team also can answer questions about what you should expect during and after your treatment.

#### Questions to ask yourself before scheduling your appointment

- Are there certain days of the week and times that work best for my schedule?
- Who is going to accompany me to the treatment, and what are the best days/times for them?
- Are there any important holidays, work events, or social activities that I would prefer not to miss?

#### What to expect from your treatment

Your treatment plan may bring about physical and mental challenges. It's completely normal to feel anxious—especially when you begin treatment and do not know what to expect. In time, though, as you learn how your body responds, you will gain confidence in your ability to recover from the treatment.

#### Questions for your healthcare team

- What specific treatments will I receive, and who will give me the treatment?
- How often will I be given treatment?
- How long will my treatments last?
- Will I need a ride home after the treatment?
- Can I eat before I have the treatment?
- Can a family member or friend accompany me during the treatment?
- Do I need to stay in the hospital after the treatment?
- Can you walk me through the treatment? What will happen during it? How will I feel? Will there be immediate or long-term side effects?
- Can I work during my treatments?
- Does my health insurance pay for my treatments?

#### Palliative care

Palliative care is supportive care aimed at improving quality of life by managing symptoms and treatment side effects. Palliative care can address the physical and emotional side effects of ovarian cancer treatment, including things like pain, sleep, loss of appetite, and nerve or muscle problems, among many others. Examples of palliative care include physical therapy and rehabilitation, nutritional changes, medications, counseling, and more.

Palliative care works alongside other types of treatment, such as chemotherapy and surgery.

Palliative care can benefit patients at any age and any stage of disease. Palliative care does not treat ovarian cancer itself but is often offered once cancer is diagnosed. It can continue until treatment is complete, although you can stop it at any time.

Visit the American Cancer Society to learn more about palliative care.



## Complementary and integrative therapies

### What are complementary and integrative therapies?

It's natural to want to fight your ovarian cancer any way you can. In recent years, increasing numbers of Americans—including those with ovarian cancer—have been turning to complementary and integrative therapies in pursuit of health and well-being. Complementary and integrative therapies are a group of diverse practices and products that are used in conjunction with standard conventional medicine.



There are countless complementary therapies, and many with ovarian cancer have benefited from them. You might want to speak with others with cancer or your healthcare team to see which therapies they found most helpful or what might work best for you and your lifestyle. Also, talk with your healthcare team before you try any of them to make sure they won't interfere with your cancer treatment.

### Differences between complementary and alternative medicine

Many people may be confused about the differences between “complementary” and “alternative” medicine, often referred to by the acronym CAM. Many medical experts prefer the more contemporary term “integrative therapy.” Complementary methods are different from alternative treatments. Complementary methods are meant to be used with and support standard treatments. Alternative methods are used instead of standard treatments. Deciding to do alternative therapies over conventional cancer treatments could put you at risk - such as delaying or interrupting standard treatments.

### Complementary and integrative therapies:

**Acupuncture:** An ancient Chinese method of healing in which very fine, sterilized needles are inserted through the skin at specific points on the body to remove blockages in your body's flow of energy. Acupuncture helps with nausea, pain, and other side effects of cancer treatment.

**Aromatherapy:** Using essential oils from flowers, herbs, and trees to promote health and well-being. It is often used to relieve nausea, fatigue, and stress.

**Biofeedback:** Biofeedback uses simple monitoring devices to teach you how to consciously regulate your breathing, heart rate, and blood pressure to reduce stress and relieve pain and muscle tension.

**Herbal medicine:** Remedies using plant parts to treat symptoms and illnesses. Herbal medicine products are dietary supplements that many people take to improve their health. Make sure you consult with your healthcare professional before using herbal medicine.

**Massage:** Manipulating the body's muscle and connective tissue through rubbing, kneading, and patting to promote relaxation and well-being.

**Meditation:** In meditation, you learn to focus your attention and suspend the stream of thoughts that usually occupy your mind. The practice is proven to result in a reduction of stress and greater relaxation of mind and body.

**Prayer:** Among all forms of complementary medicine, prayer is the single most widely used practice to improve health and well-being.

**Qi Gong (chee-GUNG):** A type of Chinese medicine that combines movement, meditation, and breathing to enhance the flow of qi (an ancient term given to what is believed to be vital energy) in the body, improve blood circulation, and enhance immune function.

**Reiki (ray-kee):** Reiki is a form of Japanese energy medicine in which a practitioner places their hands on or near the person receiving treatment, with the intent to transmit universal life energy and promote balance throughout the body.

**Tai Chi (tie-chee):** A mind-body practice that originated in China. A person doing tai chi moves her body slowly and gently while breathing deeply and meditating (tai chi is sometimes called “moving meditation”).

**Yoga:** A form of non-aerobic exercise that involves stretching and strengthening poses, breathing exercises, and meditation to calm the nervous system and heal body, mind, and spirit.

**For more information about complementary and integrative therapies, visit [cancer.org](https://www.cancer.org), or call 1.800.227.2345. Here, you'll find general information to help you better understand these terms and how to decide if they are right for you.**

## Coping with treatment side effects

Although ovarian cancer treatments are constantly improving, they may still cause side effects. For example, while chemotherapy kills the bad cancer cells in your body, it also can damage your healthy cells. This can cause unwanted side effects that vary from person to person and from one treatment to the next. The good news is many side effects can be treated. Today, measures are available to help prevent or alleviate common side effects like nausea and vomiting. There are also medicines to help minimize problems resulting from low blood counts, such as anemia or persistent infections.

You must tell your doctor and oncologist about any side effects you develop so they can prescribe any needed medication. Following is a description of some of the most typical side effects that may occur with ovarian cancer treatments.

### Treatment-induced menopause

Some treatments, such as surgery, chemotherapy, and hormone therapy, can cause early or sudden menopause. This type of menopause can happen when these treatments disrupt the normal functioning of the ovaries, leading to a halt in menstruation and symptoms typical of menopause, such as hot flashes, vaginal dryness, and mood changes. If this happens, talk with your healthcare team about how to manage and help your body adjust.

### Fatigue and anemia

Fatigue—feeling exhausted, weak, and worn out—is one of the most common side effects of cancer and cancer treatment. You may suffer from fatigue if you feel physically, emotionally, or mentally exhausted and have difficulty concentrating or thinking clearly.

One of the most common causes of fatigue in patients with cancer is anemia, a condition in which your body does not have enough red blood cells. Symptoms of anemia include extreme tiredness, headaches, heart palpitations, shortness of breath, and difficulty sleeping.

#### ROSALIND

*“Before my first round of chemo I created a survivor journal. It included healing passages, survivor stories, and the miracles I experienced in my journey. My goal is to be the best advocate I can for myself. I continue to research and print articles about granulosa cell tumors, the rare type of ovarian cancer I was diagnosed with. I make note of the top medical facilities and oncologists in my area. I attend events and talks to stay as knowledgeable as I can. I also look for ways to serve others in the cancer and survivor communities.”*

### Nausea or vomiting

Not everyone treated for ovarian cancer experiences nausea and vomiting. For those who do, the level of discomfort varies from person to person, drug to drug, and can last from hours to a day or sometimes longer.

### Hair loss

For many, losing their hair (alopecia) is one of the most devastating side effects of cancer treatment because the loss is so visible and directly linked with identity and style. Chemotherapy can cause hair loss all over the body, including eyebrows, eyelashes, arms and legs, pubic area, and underarms. Hair loss often starts two to three weeks after chemotherapy begins. To help prevent hair loss, some use cooling caps (scalp hypothermia) before treatment. Discuss the pros and cons of cooling caps with your cancer treatment doctor.

### Infection

Many chemotherapy drugs can cause a shortage in the number of white blood cells called neutrophils in your body—making you more likely to develop an infection. If you develop neutropenia—a deficiency of neutrophils—during your treatment, even minor infections can become a problem. Therefore, it is important during this period of vulnerability to take special precautions to protect yourself.

### Loss of appetite and taste changes

As you undergo cancer treatment, you may lose your appetite or interest in eating. Proper nutrition is always important, but it is essential when fighting cancer. Your doctor may refer you to a nutritionist experienced with cancer patients to develop a nutrition plan.

### Loss of fertility

Loss of fertility due to surgery for ovarian cancer can be one of the most challenging issues that women face. Women who have not finished having children or who have not yet begun to start their families may experience the loss of fertility in different ways. It is important to have strong support systems such as family members and counselors. You can find infertility support groups in the resources section of this guide.

### Mouth and throat problems

Chemotherapy drugs can affect the healthy lining of your mouth, throat, and tongue and cause difficulty swallowing. In addition, the tissue in your mouth can be irritated and dry, which can cause you to lose your appetite and develop mouth sores and infections.

## LYNDA

*“Not only did my life change drastically when I was diagnosed, but my family as a whole. I went from someone who took care of everything to everybody taking care of me. Ovarian cancer humbled me in a great way. I was diagnosed with stage four ovarian cancer at the age of 47, but I just refuse to let it define who I am.”*

### Constipation and diarrhea

During your treatment, you may have trouble passing stool (constipation) or have loose stools (diarrhea). Your cancer treatment can cause these changes in your bowel habits, changes in your diet, pain medication, and inactivity. If you experience severe stomach pain, cramping, or diarrhea for more than a day, call your doctor.

### Bowel obstruction

A bowel obstruction happens when scar tissue, often from surgery or sometimes because of a tumor, blocks your intestine. It can lead to problems like severe constipation, abdominal pain, nausea, and vomiting. If you have these symptoms, tell your doctor right away. They'll check if simple diet changes can help or if you need more serious treatments, like surgery.

### Ostomy

Advanced ovarian cancer can sometimes spread to the surface of the bowel (part of the digestive system), sometimes requiring surgery to remove some of the bowel. The affected bowel area can sometimes be removed, and the two ends joined back together. However, if not, the surgeon may need to create a new opening to eliminate waste, called an ostomy or stoma. Waste is then collected in a colostomy or stoma bag. This may be temporary or permanent.

### Nerve and muscle problems

Chemotherapy can sometimes affect the muscles and nerves, causing you to experience tingling, burning, or numbness in the hands and feet (peripheral neuropathy) or loss of balance and clumsiness. Your doctor may alter your chemotherapy drug or dosage to help reduce these symptoms.

### Skin Irritation

Chemotherapy drugs can cause rashes, itching, peeling skin, and acne. Cracked and irritated skin can be more prone to infection, so taking care of your skin during treatment is important.

## Pain

Pain is a common side effect of cancer and can be caused by a tumor pressing on nerves, bones, or organs and sometimes even by your treatments. You should speak to your doctor to determine your personalized pain-management strategy. Many cancer centers now have pain specialists and palliative care departments to help you.

### Sexual side effects

During treatment, you may not be as interested in sex as you usually are. This is understandable, given the emotional and physical stresses you are facing. Treatment side effects such as nausea, fatigue, pain, and changes in your body and appearance (e.g., hair and weight loss) can also reduce your libido. Hot flashes and vaginal dryness can also cause a lack of interest in sex.

### Sleep problems

It's not unusual to have trouble sleeping if you are in pain, under a great deal of stress, feeling ill, or are in the hospital. You might have trouble falling asleep, staying asleep, waking up earlier than usual, or only sleeping for brief periods at a time. To learn how to manage sleep problems, read our “Quality of Life” booklet.

### Memory problems

Many complain that during chemotherapy and afterward, they experience a mental cloudiness. Its cause isn't known, but it is commonly called “chemo brain” or “chemo fog.” You have trouble thinking and concentrating and may have memory lapses as well. You may also have difficulty multitasking the way you did before you had chemotherapy. The good news is that the brain usually recovers over time. However, vague mental changes may go on for years.

**For more information about managing any of the side effects discussed, read our “Quality of Life” booklet.**

## DAWN

*“I was diagnosed with Stage IV ovarian cancer at the age of 52. My symptoms included indigestion, upper abdominal bloating and fullness, and urinary frequency and urgency, which then were followed by a nagging cough and shortness of breath. I volunteer when I can to raise awareness as well as much needed funds for NOCC!”*

## CHAPTER 4 RESOURCES

The following resources offer credible programs and information that will be helpful to you as you seek information and support. Remember—especially as you seek information online—that not all sites offer scientifically validated or accurate information, and some sites can be needlessly alarming. Narrowing your search to well-known organizations and government sources will help ensure the credibility of information. For more resources, go to the NOCC’s website, [ovarian.org](http://ovarian.org).

### Patient/ Caregiver Support Organizations

**National Ovarian Cancer Coalition**  
888-OVARIAN (888-682-7426)  
[ovarian.org](http://ovarian.org)

The NOCC is the leading ovarian cancer public information and education organization in the U.S. Help and hope for ovarian cancer patients and their families is provided through a nationwide network of chapters, a toll-free information line, a comprehensive website, peer support, informational literature, and special awareness projects.

**Clarity**  
858-657-0282  
[clarityfoundation.org](http://clarityfoundation.org)

At Clarity, we provide individualized support to patients, families, and caregivers. Our support is personalized, based on each person’s needs and priorities.

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

FORCE is a nonprofit organization for people who are at high risk of developing certain cancers, including ovarian cancer,

due to their family history and genetic status and for members of families in which a BRCA mutation may be present.

**Foundation for Women’s Cancer**  
312-578-1439  
[foundationforwomenscancer.org](http://foundationforwomenscancer.org)

The Foundation provides programs to benefit those who have or who are at risk of developing gynecologic cancer. These programs raise awareness of ways to prevent, detect, and treat gynecologic cancers while providing education and support.

**Ovarcome**  
713-800-2976  
[ovarcome.org](http://ovarcome.org)

Ovarcome’s mission is to raise global awareness, fund research in search of a cure, and provide financial, psycho-social, and informational support to Ovarcomers

**Ovarian Cancer Research Alliance**  
866-399-6262  
[ocrahope.org](http://ocrahope.org)

OCRA is devoted to the formation of early diagnostic treatment programs and research toward ending ovarian cancer.

**SHARE Cancer Support**  
844-ASK-SHARE (844.275.7427)  
[sharecancersupport.org](http://sharecancersupport.org)

SHARE is a national nonprofit that supports, educates, and empowers

anyone diagnosed with breast or gynecologic cancers and provides outreach to the general public about signs and symptoms. We are a compassionate community of knowledgeable survivors, those living with cancer, and healthcare professionals. SHARE’s mission is to create and connect a community of women affected by ovarian or breast cancer with support groups, events, educational programs, and advocacy activities.

**SHARSHERET**  
866-474-2744  
[Sharsheret.org](http://Sharsheret.org)

Sharsheret, a national non-profit organization, improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support and saves lives through educational outreach.

**Unite for Her**  
610-883-1177  
[Uniteforher.org](http://Uniteforher.org)

Our mission is to enrich the health and well-being of those diagnosed with breast and ovarian cancers – for life – by funding and delivering integrative therapies.

### General Cancer Information

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

The American Cancer Society is dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer through research, education, advocacy, and service.

**Cancer.Net**  
888-651-3038  
[cancer.net](http://cancer.net)

Links all American Society of Clinical Oncology information and materials to help patients and families make informed healthcare decisions.

**National Cancer Institute**  
800-4-CANCER (800-422-6237)  
[cancer.gov](http://cancer.gov)

An arm of the U.S. National Institutes of Health (NIH), the NCI provides comprehensive information about cancer, cancer clinical trials, and the latest research developments.

**National Center for Complementary  
and Integrative Health**  
888-644-6226  
[nccih.nih.gov](http://nccih.nih.gov)

The nation’s lead agency for scientific research into the diverse medical and healthcare systems, practices, and products that are not generally considered part of conventional medicine.

**National Coalition for Cancer  
Survivorship**  
877-NCCS-YES (877-622-7937)  
[canceradvocacy.org](http://canceradvocacy.org)

The country’s oldest survivor-led advocacy group provides information on cancer support, advocacy, and quality-of-life issues.

**National Comprehensive Cancer  
Network - NCCN**  
[nccn.org](http://nccn.org)

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 33 leading cancer centers devoted to patient care, research, and education. NCCN Guidelines for Ovarian Cancer: <https://www.nccn.org/patients/guidelines/content/PDF/ovarian-patient.pdf>



**Society for Gynecologic Oncology**  
[sgo.org](http://sgo.org)

Our mission is to prevent and treat gynecologic cancers with equity, improving lives through advocacy, engagement, education, research, and collaboration.

## Additional Patient/ Caregiver Support Organizations

**Bright Pink**  
[brightpink.org](http://brightpink.org)

Bright Pink is a national organization that provides education and support to young women who are at high risk for ovarian and breast cancer.

**CancerCare, Inc.**  
800-813-HOPE (800-813-4673)  
[cancercare.org](http://cancercare.org)

CancerCare is a national nonprofit organization that provides free professional support services to anyone affected by cancer: survivors, caregivers, children, loved ones, and the bereaved.

**Cancer Hope Network**  
877-HOPENET  
[cancerhopenetwork.org](http://cancerhopenetwork.org)

Provides free and confidential one-on-one support to cancer patients and their families. Cancer patients or family members are matched with trained volunteers who have undergone and recovered from a similar cancer experience.

**Cancer Support Community**  
877-793-9355  
[cancersupportcommunity.org](http://cancersupportcommunity.org)

In 2009, Gilda's Club Worldwide and The Wellness Community joined forces to become the Cancer Support Community. CSC provides support and networking groups, counseling, education and

healthy lifestyle programs through a network of more than 50 local affiliates and 100 satellite locations. Listings of local Gilda's Clubs can be found through the CSC website.

**Caring Bridge**  
651-452-7940  
[caringbridge.org](http://caringbridge.org)

Provides free websites that connect people experiencing a significant health challenge to family and friends.

**LIVESTRONG**  
855-220-7777  
[livestrong.org](http://livestrong.org)

Helps those with cancer and their loved ones live strong through education, advocacy, public health events, and research.

**Look Good Feel Better Foundation**  
[lookgoodfeelbetter.org](http://lookgoodfeelbetter.org)

The program offers complimentary group and virtual sessions that teach beauty techniques to help people with cancer face their diagnosis with greater confidence.

**Lotsa Helping Hands**  
[lotsahelpinghands.com](http://lotsahelpinghands.com)

This free website helps families, friends, colleagues, and neighbors create a private community to keep track of appointments, meals, rides, daily tasks, and who has volunteered to do what.

**MyLifeLine**  
[mylifeline.org](http://mylifeline.org)

Provides free, personal websites for cancer patients to connect with their friends and family during the treatment process.

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

This organization is an active liaison between the patient and their insurer, employer, and/or creditors to resolve insurance, job retention, and/or debt crisis matters related to their diagnosis. The staff includes case managers, doctors, and attorneys.

## Fertility Resources

**The National Infertility Association**  
703.556.7172  
[resolve.org](http://resolve.org)

The National Infertility Association, established in 1974, is dedicated to ensuring that all people challenged in their family-building journey reach resolution through being empowered by knowledge, supported by community, united by advocacy, and inspired to act.

**Livestrong Fertility**  
855.220.7777  
[livestrong.org](http://livestrong.org)

Livestrong Fertility is dedicated to providing reproductive information, resources and financial support to survivors whose cancer and its treatment present risks to their fertility.

## Travel & Housing Organizations

**Air Charity Network**  
877-621-7177  
[aircharitynetwork.org](http://aircharitynetwork.org)

A network of seven organizations that provide free flights for patients who need to travel for medical treatment.

**American Cancer Society  
Hope Lodge Program**  
800-ACS-2345 (800-227-2345)  
[cancer.org](http://cancer.org)

The ACS Hope Lodges offer free housing to patients and their caregivers when traveling out of town for treatment.

**Joe's House**  
877-563-7468  
[joeshouse.org](http://joeshouse.org)

Joe's House provides a nationwide online service to help patients and their families find lodging near treatment centers.

**National Association of Hospital  
Hospitality Houses, Inc.**  
800-542-9730  
[nahhh.org](http://nahhh.org)

Offers accommodations to families and their loved ones receiving medical treatment away from home.

## Insurance and Financial Resources

It's essential to have and keep good medical insurance since there are many expenses associated with managing cancer. Perhaps you have private insurance through an individual or employee group plan.

If you are not insured, here are some options to consider:

- Check whether you can apply for insurance through professional or fraternal organizations, such as those for teachers, social workers, or retired individuals.
- Explore whether you are eligible for Medicare, which covers most people 65 or older or who are permanently disabled.
- You can find help through private insurance or public programs. Go to [www.healthcare.gov](http://www.healthcare.gov) for information on what is available in your state.
- Find out if you are eligible for Medicaid or can receive state or local benefits if you are in a low-income bracket.
- It's important to keep records of your medical bills, insurance claims, and payments, especially if you want to take advantage of the deductions available when filing an itemized tax return. Contact the Internal Revenue Service ([www.irs.gov](http://www.irs.gov)) for information and free publications regarding tax exemptions for cancer treatment expenses.
- Many drug manufacturers have patient assistance programs for those who cannot afford their medication. Check with your physician or the drug manufacturer directly to discuss the options.

### Patient Advocate Foundation

800-532-5274

[patientadvocate.org](http://patientadvocate.org)

This organization serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job retention, and/or debt crisis matters related to their diagnosis. The staff includes case managers, doctors, and attorneys.

## Finding Mental and Emotional Support Resources

Getting help during a cancer diagnosis is important. Friends, family, or a support group can make you feel better when things are tough. They give comfort, stop you from feeling alone, and help you feel like you belong. This kind of support also helps with stress and worry, which is important for your mental health while dealing with the diagnosis and treatment.

Plus, practical support can make a big difference. Friends and family can help with everyday things like shopping, cooking, or taking you to

appointments. This lets you concentrate on getting better without stressing about the daily stuff. When you get both emotional and practical support, it forms a strong network that helps you deal with cancer in a better way.

**Sometimes, we need help when going through cancer treatment. Ask for help if you need it. It makes friends and family feel good to help you.**

For more information about talking with family and friends, please access NOCC's brochure entitled "When a Loved One Has Ovarian Cancer," which is available at [ovarian.org](http://ovarian.org).

An ovarian cancer diagnosis can often leave you feeling isolated. But you are never alone. NOCC's Teal Hearts Network (ovarian cancer survivors) and Teal Cares Network (caregivers) are peer-to-peer online support groups that allow you to connect with other survivors and/or caregivers for the emotional support needed to navigate this journey. These groups are open to anyone with a current or past diagnosis of ovarian cancer.

**Teal Hearts Network -  
Survivor Peer-to-Peer Support Group**  
1.888.OVARIAN  
[nocc@ovarian.org](mailto:nocc@ovarian.org)  
[ovarian.org](http://ovarian.org)

Join a regional or shared experience support group, where you'll be embraced by a compassionate community of those living with ovarian cancer at all stages of their journey. Contact the NOCC to find a regional group and learn how to join.

**Teal Cares Network-  
Caregiver Peer-to-Peer  
Support Group**  
1.888.OVARIAN  
[nocc@ovarian.org](mailto:nocc@ovarian.org)  
[ovarian.org](http://ovarian.org)

Join NOCC's caregiver support group which provides a space for caregivers to connect and share their experiences unique to the needs of caring for a loved one with ovarian cancer.

Contact the NOCC to learn more about the group and how to join.

**SHARE Cancer Support**  
844-ASK-SHARE (844-275-7427)  
[sharecancersupport.org/ovariancancer](http://sharecancersupport.org/ovariancancer)

Whether you've been newly diagnosed with ovarian cancer, are in treatment, are a long-term survivor, or are concerned

about your ovarian cancer risk, we have support and information for you.

**CANCERcare**  
1-800-813-4673  
[cancercaresupport.org](http://cancercaresupport.org)

A national nonprofit offering free online and telephone support groups for anyone affected by cancer. Cancer Care also offers face-to-face support groups for those living in the New York Tri-State area. Professional oncology social workers lead all the support groups.

**Cancer Hope Network**  
1-800-552-4366  
[cancerhopenetwork.org](http://cancerhopenetwork.org)

A nonprofit that provides free and confidential one-on-one support to cancer patients and their families. It also offers a social network to exchange experiences and share thoughts.

**Cancer Support Community**  
1-888-793-9355  
[cancersupportcommunity.org](http://cancersupportcommunity.org)

This nonprofit offers a variety of free online support groups for people with cancer and their loved ones.

## CHAPTER 5

# GLOSSARY OF CANCER TERMS

The following glossary includes many terms you will be hearing regularly and may be helpful to you throughout your cancer treatment.

**Alopecia:** Partial or complete loss of hair resulting from chemotherapy or radiation.

**Anemia:** A condition in which the body does not have enough red blood cells. This may be due to bleeding or lack of blood production by the bone marrow. Symptoms include tiredness, shortness of breath, and weakness.

**Angiogenesis inhibitors:** A type of targeted therapy that limits the blood supply that a tumor needs to grow and thrive. (Example: Bevacizumab (Avastin))

**Antiemetics:** Drugs given to minimize or prevent nausea and vomiting.

**Ascites:** An accumulation of fluid within the abdomen that can occur in those with noncancerous conditions and with different types of cancers.

**Benign:** Non-cancerous.

**Biomarkers:** Genes, proteins, and other substances that can provide information about cancer and can be helpful in deciding which treatment to use and when.

**Biopsy:** A surgery performed to remove tissue for examination in order to determine whether cancer is present.

**BRCA 1:** Short for BReast CAncer gene 1, a gene that normally protects you from getting cancer. Mutations in this gene increase breast cancer and ovarian cancer risk.

**BRCA 2:** Short for BReast CAncer gene 2, a gene that normally protects you from getting cancer. Mutations in this gene increase breast cancer and ovarian cancer risk.

**CA-125:** A blood protein that can be measured and is an important tumor marker in ovarian cancer.

**CBC (Complete Blood Count):** A series of tests including red and white blood cell platelet counts as well as hemoglobin and cell volume measurement.

**Cancer:** Any of a group of diseases whose symptoms are due to the unrestrained growth of cells in one or more of the body's organs or tissues.

**Carcinogens:** Substances known to cause and/or promote cancer.

**Carcinoma:** Cancer that begins in the internal tissues.

**Catheter:** A flexible tube through which fluids enter or leave the body.

**Chemo Brain:** Cognitive impairment during and sometimes after chemotherapy.

**Cyst:** A fluid-filled sac.

**Diagnosis:** The act of identifying a disease from its signs and symptoms.

**Edema:** Swelling due to the accumulation of fluid within the tissues.

**Egg:** A single cell released from the ovaries that can develop into an embryo when fertilized.

**Epithelial:** Type of tissue lining the skin and hollow organs.

**Estrogen:** Female sex hormone secreted primarily by the ovaries that is responsible for secondary sex characteristics such as the growth of breasts.

**Estrogen Receptor Test:** A test done during the biopsy of cancerous tissue to determine if its growth depends on estrogen.

**Germ Cells:** Reproductive cells that produce eggs.

**Gynecologic Oncologist:** A doctor specializing in treating cancers of the female reproductive organs.

**HE-4 Test:** Blood test to monitor the recurrence or progression of ovarian cancer.

**Hematologist:** A physician (internist) who specializes in blood diseases.

**Hormones:** Naturally occurring substances that are released by the endocrine organs and circulated in the blood. Hormones control growth, metabolism, reproduction, and other functions.

**Hysterectomy:** Surgical removal of the uterus and, sometimes, the cervix. Removal of the entire uterus and the cervix is referred to as a total hysterectomy.

**Immunotherapy:** A type of treatment that uses your body's immune system to fight cancer.

**Infusion:** Slow intravenous delivery of a drug or fluids.

**Intraperitoneal:** Administration of drugs directly within the peritoneal cavity. Also called IP.

**Intravenous:** Administration of drugs or fluids directly into a vein.

**Invasive:** To invade refers to the ability of cancer cells to enter and permeate new sites in the body. A malignant ovarian tumor can grow and invade organs next to the ovaries, such as the fallopian tubes.

**Malignant:** A term used to describe a cancerous tumor.

**Menopause:** The point at which menstruation ceases. Menstruation ceases, marking the end of a woman's reproductive years.

**Metastasis:** The spread of cancer to one or more sites elsewhere in the body.

**MRI (Magnetic Resonance Imaging):** A sophisticated technique to examine the body using powerful electromagnets, radiofrequency waves, and a computer to produce internal pictures of the body.

**Neutropenia:** An abnormal decrease in the number of neutrophils, a type of white blood cell.

**Omentum:** A fold of fatty internal abdominal tissue where ovarian cancer often spreads.

**Oncologist:** A physician specializing in cancer therapy and handling general medical problems that arise during the disease.

**Oophorectomy:** Surgery to remove one or both ovaries.

**Outpatient:** A patient who has diagnosis or treatment at a healthcare facility without spending the night.

**PARP Inhibitors:** A type of targeted cancer drug that makes it hard for cancer cells to repair damaged DNA.

**Pelvis:** The lower part of the abdomen, located between the hip bones.

**Peripheral Neuropathy:** A possible side effect of chemotherapy that affects the nervous system. Symptoms include tingling, burning, weakness, or numbness of the hands or feet.

**Peritoneum:** The smooth transparent membrane that lines the cavity of the abdomen.

**PET Scan:** A diagnostic procedure in which a small amount of radioactive sugar is injected into a vein and the body is scanned.

**Port:** An implanted device through which drugs can be infused without repeated needle sticks.

**Progesterone:** A type of hormone made by the body that plays a role in the menstrual cycle and pregnancy.

**Progesterone receptor testing:** A test done during the biopsy of cancerous tissue to determine if its growth depends on progesterone.

**Prognosis:** A statement about the likely outcome of disease in a particular patient.

**Protocol:** A formalized plan for treatment.

**Recurrence:** The return of cancer after treatment.

**Red Blood Cells:** Cells that carry oxygen to all parts of the body. Also called RBC.

**Remission:** A temporary or permanent stage when cancer is not active, and symptoms disappear. A remission may not be a cure.

**Scan:** A study using X-rays to produce images of internal body organs.

**Second-look Surgery:** Surgery performed after primary treatment to determine whether tumor cells remain.

**Staging:** Designation indicating how far a cancer has progressed, based on the size of the primary tumor and on whether and where it has spread.

**Stromal Cells:** Cells that make the hormones estrogen and progesterone.

**Targeted Therapy:** A type of treatment that uses drugs to target cancer cells without harming normal cells.

**Thrombocytopenia:** An abnormally low number of platelets due to disease, reaction to a drug, or toxic reaction to treatments.

**Transfusion:** The administration of donated blood.

**Tumor:** A lump, mass, or swelling. A tumor can be either benign (non-cancerous) or malignant (cancerous).

**White Blood Cells:** Cells that help the body fight infection and other diseases. Also called WBC.



## Guiding Words

Now that you've had a chance to read this guide, you are armed with information that will help you through this difficult time. We know that the information may seem overwhelming at first. We've been there too.

Take a deep breath! This is just the beginning of your journey. You are not alone, and you will get through this with the help of your doctors, healthcare team, family, friends, and all of us at the National Ovarian Cancer Coalition.

Treatment options for those with ovarian cancer are undergoing a revolution. There are hundreds of drugs currently being studied to improve treatment outcomes.

You must be your own best health advocate. If you have a question about your treatment, seek a second or even a third opinion. You can also read our "Quality of Life Issues" booklet to learn how to manage side effects from ovarian cancer treatment.

In the meantime, find a board-certified gynecologic oncologist—a doctor who specializes in the diagnosis and treatment of women with cancer of the reproductive organs. Over the past two decades, research has shown that surgery by a gynecologic oncologist is one of the top factors in increasing ovarian cancer survival rates.

Remember, the NOCC and our local markets are on your side and always here to help. We're a click away at [ovarian.org](http://ovarian.org) or call us at 1-888-OVARIAN (1-888-682-7426).

The more information you have at your fingertips, the easier it will be to work with your healthcare team, manage your cancer, and make the best decisions for you.



## Find a Community Near You

Our communities span the country, encompassing local markets that make up our regions essential to fulfilling the NOCC mission. For survivors and their caregivers, it's a compassionate connection to ovarian cancer support groups, educational programs, events, and links to information and resources that follow them throughout their journey. For volunteers, it's the hub for donating the time and resources we need to raise awareness, support survivors and caregivers, fund research, and find a cure.



To find a community near you, visit:  
[ovarian.org](http://ovarian.org)



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](mailto:nocc@ovarian.org)

[ovarian.org](http://ovarian.org)

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