



RESOURCE GUIDE FOR THOSE WITH  
**RECURRENT OVARIAN CANCER**





## ABOUT THE NATIONAL OVARIAN CANCER COALITION®

Since 1991, the National Ovarian Cancer Coalition (NOCC) has supported thousands of cancer survivors, delivered millions of educational resources and connected with 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).

**Finding out that you have ovarian cancer is a shock.** But finding out it has come back can be even more of a shock. You may think to yourself, “How could this be happening to me? Haven’t I been through enough already?” But the reality with ovarian cancer is it is likely to recur. Many are diagnosed with a recurrence months or years after treatment, and many go in and out of remission for months or even years.

If your cancer has recurred, this can be a challenging time for you and your family. You’ve been down this road before, but this is a new journey. Draw on the strength that helped you get through your initial diagnosis. Try to stay positive, empower yourself with information, channel your strength, and, most of all, remain hopeful. There are effective medical treatments for recurrent cancer.

This guide is designed to help you make informed decisions about your treatment and be proactive in managing your health. It is not meant to take the place of direct communication with your treatment team. Inside the guide, you will find stories shared by others who have also had recurrent ovarian cancer. The more you know, the easier it will be to make decisions that are best for you. Remember, there is a lot of information out there. Gather information from credible sources, such as your healthcare team, leading cancer advocacy organizations, cancer centers, and reputable websites.

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

For more information about ovarian cancer treatment and living well after an ovarian cancer diagnosis, visit [ovarian.org](https://ovarian.org).



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### Why Does Ovarian Cancer Recur?

For anyone who has had ovarian cancer, the end of treatment is not the end of fear. For months, if not years, afterward, you may worry your cancer is back every time you feel the slightest ache or pain. No matter how long it's been since you finished treatment, there are certain times—checkup appointments, blood tests, the moment you read something scary about cancer—when you worry more about your cancer recurring.

Although most ovarian cancers respond well to initial chemotherapy treatments, the disease often comes back (or recurs) after treatment. This happens because some cancer cells that were not destroyed with the first treatment remain in the body. Some of these cells might have been too small to be found.

If your cancer does recur, it's important to remember that no matter what, you and your healthcare team now know more about ovarian cancer than you did when you were first diagnosed. You, your doctor, and your healthcare team will focus on controlling the spread of cancer by personalizing care and using the most effective treatments available.

### How Is a Recurrence Diagnosed?

After initial treatment, your gynecologic oncologist will keep track of your health and look for any signs of recurrence using several blood tests, scans, and physical exams. Symptoms of recurrence may include abdominal pain, bloating, changes in bowel or bladder habits, and unexplained weight loss (or weight gain due to ascites). Regular follow-up visits and monitoring are essential for finding a recurrence and identifying signs of cancer returning at the earliest possible stage. Finding a recurrence as early as possible allows for quick treatment, greatly improving treatment outcomes and prolonging survival.

When ovarian cancer returns, it can happen in different ways:

- **Local Recurrence:** The cancer comes back in the same place it originally started.
- **Regional Recurrence:** The cancer comes back in the nearby lymph nodes.
- **Distant Recurrence:** The cancer comes back in a different part of the body.

Your healthcare team can explain your type of recurrence and what it means for your treatment and prognosis.

One blood test often used for monitoring recurrence is the CA-125 blood test. This test is helpful but not perfect. It measures the amount of a protein called CA-125 in the blood. It's useful but not as accurate because not everyone with ovarian cancer has high levels of CA-125. The test can also show if treatment is working, as CA-125 levels often decrease with successful treatment. However, it's not clear if watching CA-125 levels helps improve outcomes. A CA-125 level of 35 or under is considered normal. Levels above 35 may indicate something abnormal. Those with ovarian cancer often have levels in the hundreds. Remember that an increasing level does not always mean the cancer is back. Talking with your doctor about which CA-125 levels concern you is important.

### What does “time to recurrence” mean?

Understanding “time to recurrence” is important when talking about ovarian cancer. This term refers to the time between finishing the first treatment (with platinum-based chemotherapy) and the cancer coming back. In ovarian cancer, this is important to know as it helps determine how effective the first treatment was and can help inform future treatment decisions.

### Platinum-sensitive and platinum-resistant cancers

Depending on how fast the cancer came back may indicate how effective the treatment was. Ovarian cancer is generally classified as either platinum-sensitive or platinum-resistant:

- **Platinum-sensitive ovarian cancer** means the cancer responds well to a type of chemotherapy drug (called cisplatin or carboplatin). If it comes back (or recurs), it usually takes a long time - more than six months after the last treatment.
- **Platinum-resistant ovarian cancer** means the cancer did not respond well to chemotherapy. If it comes back, it happens quickly, usually within six months after the last treatment.

Several factors can influence the time to recurrence, including the stage of the cancer at diagnosis, the grade of the tumor, and your overall health. The time between treatments and recurrence affects which treatments might work. This classification helps doctors decide the type of chemotherapy to use for treating recurrent ovarian cancer.

## 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 and or a medical oncologist
- Oncology nurses
- Nutritionist
- Social worker
- Office or clinic receptionist
- Psychologist
- Nurse practitioner
- Physical therapist
- Patient navigator

### Questions to consider when choosing a doctor:

- Is your doctor a gynecologic oncologist?
- Are they experienced in treating your kind of recurrent 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?
- 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?



## 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.

### Questions to ask when getting a second opinion

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

## Communicating with your healthcare team

After you find out that you have a recurrence of 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.

### ALICIA

*"Having Ovarian Cancer twice changed my life by causing me to slow down and enjoy every moment in life. As a survivor friend once told me, "Of course, it goes without saying that your life has changed forever, but not necessarily the way you think. There are just as many beautiful aspects to this as scary ones." Look for the beauty in each and every day because it is there and will give you strength to keep going."*



## Getting the most out of your doctor visits

In reality, even the most caring and communicative doctors have hectic schedules and may need more time to spend with their patients during each visit. Preparing in advance can help you make the most effective use of your medical appointments.

- 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 another person and a notepad with you. 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. Also, it is 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 so 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. Respect 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 how you feel.

## CHAPTER 2 UNDERSTANDING TREATMENT OPTIONS FOR RECURRENT OVARIAN CANCER

Sometimes ovarian cancer responds to treatment when it recurs, but sometimes not. Some individuals will have "stable disease" on treatment. This means the tumor will not grow but will not shrink significantly either. When cancer is stable during treatment, and the treatment is well tolerated, most doctors will recommend continuing that treatment until the treatment is no longer effective. Sometimes, the cancer does not respond to the treatment and grows, which is called "progressive disease."

Treatment for recurrent ovarian cancer is not the same for everyone. There have been advancements in treatments for recurrent ovarian cancer, including targeted therapies, immunotherapy, and clinical trials. The treatment recommended will depend on the type, duration, and response to the original treatments and the location and extent of the newly diagnosed cancer. Developing a personalized treatment plan depends on the kind of tumor you have. It also depends on your age, desire to have children naturally, and overall health. Treatments for recurrent ovarian cancer may include surgery, chemotherapy, targeted therapy, immunotherapy, hormone therapy, and radiation.

Once you have been diagnosed with a recurrence, there are many important treatment-related issues to consider, such as:

- When should treatment begin?
- Should I have surgery?
- How will the medications used affect my overall health?
- Should I participate in a clinical trial?
- Should I get a second opinion?

As you consider your options, you should consider your goals and your doctor's goals for treatment. For most people, the most important goal is to keep cancer under control. However, it is also important to discuss other important goals, such as controlling the side effects of treatment and maintaining the highest possible quality of life.

### Treatment based on rising CA-125

There are many differing opinions on starting treatment for a possible recurrence based on rising CA-125 levels alone. While increasing CA-125 can be alarming, it doesn't always mean a recurrence, as other conditions can cause temporary increases.

If there's no evidence of recurrence, discuss with your doctor whether to start treatment based on rising CA-125 levels, as each case is unique.

## DIANE

*"I am loving life at 68 years old and four years and three months post my last chemo for ovarian cancer 3C. I had an excellent surgeon & my 3rd oncologist & my naturopath got me through the chemo. I thank God for answering the prayers of my family, friends, church, and myself to extend my life."*

## Developing a Treatment Plan Specific to You

Once you and your doctor have discussed your treatment options, you will work together to develop a treatment plan specific to you (personalized). There are many treatments available for treating a recurrence of ovarian cancer. Your doctor may consider the following when making a personalized treatment plan:

- The time to recurrence - the time between finishing the first treatment (with platinum-based chemotherapy) and the cancer coming back.
- The number of prior treatments given and the specific drugs used (platinum-resistant or sensitive)
- The type and severity of side effects from prior treatments
- Your current health status
- The location and size of the tumor
- Current symptoms
- Personal goals for additional treatment

The following is a list of questions that you and your doctor can discuss as you make important treatment decisions:

- Will I need additional surgery?
- Will I need additional imaging?
- 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 the recommended treatment? 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? Will I be able to care for my family?
- Can you recommend a counselor for me to talk to?
- Are there any clinical trials in which I am eligible to participate?

## The role of genetic and biomarker tumor testing in treatment

### Genetic testing for an inherited mutation

Current guidelines recommend all patients with ovarian, fallopian tube, and primary peritoneal cancer should have genetic testing that looks for any genetic mutations you may have inherited from a parent. This is called germline genetic testing, which should be done at the time of initial diagnosis. If you did not get genetic testing at the time of your initial diagnosis, now is the time to consider it. Germline genetic testing looks for any genetic changes you may have inherited from your parents.

This is important because if you have an inherited gene mutation (germline mutation), you might be more likely to get other types of cancer as well. In addition, your family members might also benefit from knowing this so they can get tested and manage their own risk. Approximately 20-25% of those diagnosed with ovarian cancer have gene mutations that make them more likely to get ovarian cancer, most commonly mutations in the BRCA1 or BRCA2 genes. If you have a BRCA1 or BRCA2 mutation, you may benefit from a targeted treatment with PARP inhibitors at some point. However, other genetic mutations can also increase the risk of ovarian cancer.

Speaking with a genetic counselor to help you understand the risks, benefits, and what to expect from testing is a good idea. There are many things to consider before getting tested, such as how this might affect your family, if more medical tests are needed, and privacy issues. Speak to your healthcare provider about meeting with a genetic counselor who can walk you through the process.



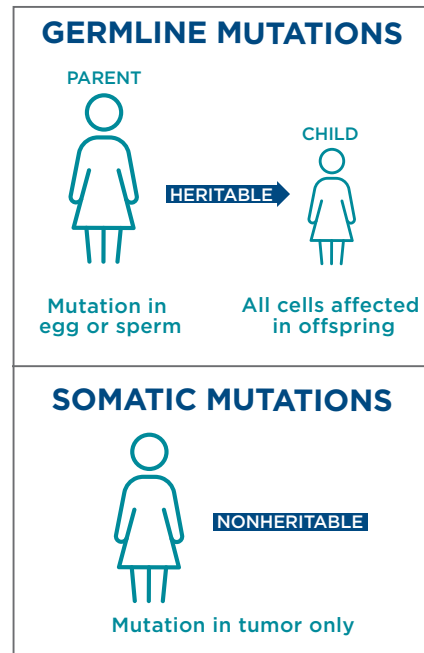
## Genetic testing of the tumor

In addition to testing for an inherited genetic mutation, the tumor itself can have a mutation in its genes. This is called a somatic mutation (a change in the DNA of the tumor that developed at some point in time). Certain treatments, such as PARP inhibitors, are available for these types of mutations.

It is recommended for those with recurrent ovarian, fallopian tube, or primary peritoneal cancer to have somatic genetic testing when no mutation is found in germline testing. Testing of the genes in the tumor itself can help your doctor understand the cancer better and what treatment options might be available. This testing can be performed on tumor tissue samples from surgery or biopsy.

Germline mutations are inherited and found in all your body's cells. Germline genetic testing looks for genetic mutations inherited from either parent.

Somatic mutations are not inherited and are found in the tumor. Somatic genetic testing tests the tumor for genetic mutations found in the tumor itself.



## Biomarker testing (tumor testing)

In addition to genetic testing, the tumor can be tested to look for other substances, called biomarkers, that can help doctors learn how your cancer behaves and how to best treat it. Biomarker testing is also called tumor testing. Biomarkers are proteins or other genetic changes a tumor makes and are found in the blood and tissue. Biomarker testing may help predict how fast the cancer grows and which treatments may work best - such as targeted 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 biomarkers that may be found are listed below, along with the treatments usually recommended:

- BRCA1/BRCA2 mutations - if you have one of these mutations, you may likely respond to treatment with PARP inhibitors such as Lynparza (olaparib)/Rubraca (rucaparib)/Zejula (niraparib)
- HRD (Homologous Recombination Deficiency) - if your tumor is HRD positive, you may likely respond to treatment with PARP inhibitors such as Avastin (bevacizumab)/Lynparza (olaparib)/Zejula® (niraparib)

- HER2 (Human Epidermal Growth Factor Receptor 2) - if your tumor overexpresses HER2, you might likely respond to targeted therapies like Trastuzumab deruxtecan (T-DXd).
- FRa (folate receptor alpha) - if your tumor has specific levels of folate receptor alpha, you might likely respond to targeted therapies like Elahere (mirvetuximab soravtansine)
- ER/PR (estrogen/progesterone) - if your tumor is either ER or PR positive, you might likely respond to hormone therapy like tamoxifen (Nolvadex) or letrozole (Femara)

Tumor testing can also reveal mutations and biomarkers that could point you toward a clinical trial, which is another option to receive treatment while participating in developing new therapies. Whether tumor testing identifies options for FDA-approved targeted therapies for ovarian cancer, other approved therapies, or clinical trials, testing the tumor is a way for you to benefit from precision medicine by finding the treatment options best matched to your specific cancer.

Visit the American Cancer Society to learn more about biomarkers.

## Treatment for platinum-sensitive cancer

When ovarian cancer comes back, doctors usually describe it as either platinum-sensitive or platinum-resistant. This depends on how long it has been since you last had chemotherapy containing platinum-based chemotherapy (carboplatin or cisplatin). If you experience a recurrence more than six months after completing your initial therapy, your cancer is considered platinum-sensitive. This means that platinum-based chemotherapy drugs work well in treating the cancer.

- Treatment options for platinum-sensitive patients can include additional surgery, chemotherapy, and targeted therapy. If your doctor does not mention it, it is also important to ask about any clinical trials you might be eligible to participate in.
- Surgery may be recommended to remove as much of the cancer as possible before starting chemotherapy again. The decision to perform surgery depends on various factors, including the location and extent of the recurrence, the individual's overall health status, and previous treatments received.
- Chemotherapy using platinum-based drugs are usually recommended again if it worked well the first time. In some cases, other chemotherapy drugs will be used as well. This is usually in combination with another drug, such as paclitaxel (Taxol®), pegylated liposomal doxorubicin, or gemcitabine [Gemzar].
- Maintenance therapy - your doctor may also recommend the following to try and prevent cancer recurrence:



- Bevacizumab (Avastin) - a drug used to treat ovarian cancer by preventing the growth of new blood vessels in the tumor. It is used in combination with chemotherapy, followed by maintenance.
- PARP Inhibitors - poly (ADP-ribose) polymerase (PARP) inhibitors work by stopping certain repair processes in cancer cells. These may be recommended for maintenance after a complete or partial response to chemotherapy for platinum-sensitive disease. PARP inhibitors have the greatest effect in those who test positive for BRCA and HRD genetic mutations but also appear to benefit patients with different genetic profiles as well.

## Treatment for platinum-resistant cancer

If you experience a recurrence within six months after completing your initial therapy, your cancer is considered platinum-resistant. This means that platinum-based chemotherapy drugs were not as effective in treating the cancer. If you have platinum-resistant cancer, it is unlikely you will benefit from re-treatment with a platinum-based regimen. However, several alternative chemotherapy drugs can be used to treat recurrence.

Treatment options for those who are platinum-resistant can include additional surgery, chemotherapy, targeted therapy, hormone therapy, and radiation therapy. Not all treatments are suitable for everyone. Your doctor will talk to you about what drug might be helpful in your situation. If your doctor does not mention it, it is also important to ask about any clinical trials you might be eligible to participate in.

- Surgery may be recommended to remove as much of the cancer as possible before starting chemotherapy again. The decision to perform surgery depends on various factors, including the location and extent of the recurrence, the individual's overall health status, and previous treatments received.
- Chemotherapy using carboplatin will likely not be recommended again therefore, your doctor may suggest one or more of the following treatments:
  - paclitaxel alone, usually as a weekly treatment
  - liposomal doxorubicin
  - gemcitabine
  - etoposide
  - cyclophosphamide
- Targeted therapies - cancer treatments that specifically target and attack cancer cells while causing less harm to healthy cells:

- Bevacizumab (Avastin) - prevents the growth of new blood vessels in a tumor. Just like platinum-sensitive cancers, your doctor may also recommend bevacizumab (Avastin) in combination with chemotherapy, followed by bevacizumab maintenance.
- Poly (ADP-ribose) polymerase (PARP) inhibitors - work by stopping certain repair processes in cancer cells. They may be recommended for maintenance after a complete or partial response to chemotherapy for platinum-sensitive disease. PARP inhibitors have the greatest effect in those who test positive for BRCA and HRD genetic mutations but also appear to benefit patients with different genetic profiles as well. Examples of PARP inhibitors include Olaparib (Lynparza), niraparib (Zejula), and rucaparib (Rubraca).
- Antibody-Drug Conjugates (ADC) - this class of drugs selectively delivers chemotherapy directly to the tumor. Mirvetuximab soravtansine (Elahere) is an ADC that is used to treat epithelial ovarian cancer that tests positive for a protein called FRa (FRalpha), and that is no longer responding to and chemotherapy drugs such as cisplatin or carboplatin.
- Immunotherapy - treatment that uses your body's immune system to fight cancer. Immunotherapy also helps your body produce cancer-fighting immune cells. While immunotherapy has shown promise in some patients with ovarian cancer, it is not yet a standard treatment for all patients. Research in this area is ongoing, with the hope of identifying effective immunotherapy strategies that can improve outcomes for patients with ovarian cancer. An example of immunotherapy is pembrolizumab (Keytruda).
- Hormone therapy - 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. Examples of hormone therapy are Tamoxifen, aromatase inhibitors such as anastrozole (Arimidex®) or letrozole (Femara), goserelin (Zoladex®), and leuprolide (Lupron). These medications either lower the levels of estrogen or stop the body from making certain hormones.
- Radiation therapy - occasionally, radiotherapy is recommended for advanced ovarian cancer. Radiotherapy can shrink tumors and reduce symptoms. This is called palliative radiotherapy. Your doctor might also use radiotherapy to treat cancer that has spread outside the abdomen.

### Should You Consider Surgery?

While surgery is an important part of the initial diagnosis and treatment of ovarian cancer, it is unclear whether surgery benefits patients after a recurrence. In most cases of recurrent disease, the cancer is not in a single mass that the surgeon can easily remove. Make sure to have this important discussion with your surgeon.

## 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.

### Is a clinical trial right for you?

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; not every person is 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;
- you can withdraw from a clinical trial at any time.

### 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?

### ALICIA

*"Participating in a clinical trial is the best thing I ever did. I have been cancer free for four years now. For me, participating in a trial was also important as a way to give back. I feel I am helping to open the door for patients down that road that need treatments like PARP inhibitors".*



Alicia Dellario  
West Chester, Pennsylvania



**To learn more, scan QR code to watch a video of Alicia's story.**

## Clinical trial resources: Where do I begin?

The 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

Emergingmed.com can assist in looking for clinical trials by filling out a short questionnaire.

### The Center For Information And Study On Clinical Research Participation (CISCRP)

877-633-4376

ciscrp.org

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

## MARY

*“Recurrence was harder to accept than my original diagnosis, but once I caught my breath, I realized that the most important thing to do is to trust in myself and my medical and support teams. With the new PARP inhibitors recently approved for recurrent ovarian cancer, my chances of extending my life are better than they ever were. An attitude of gratitude is my mantra, and it has served me well for four years and counting.”*



## Questions to Ask Your Doctor About Treatment Options

If you are diagnosed with recurrent cancer, your doctor will develop a treatment plan. Planning treatment is quite similar to planning treatment for your primary cancer.

### Here are some questions to ask:

#### Key considerations

- What stage (extent) is my cancer, and what does that mean? Has my cancer spread beyond the ovaries? If so, what does this mean for me?
- Were any other tests done on my tumor that provide more information about my type of cancer? Will other tests be needed? If so, what kind? (genetic testing, biomarker testing)
- Is my case being presented at a tumor board meeting?
- What are my treatment options? Is surgery an option? Which do you think would be best for me?
- Is the treatment the same or different from my last treatment?
- How long will I be on this treatment?
- How soon should treatment be started?
- How successful is the treatment that you recommend for me?

#### Side effects

- Will I have side effects? If so, are they different from those I am already experiencing? How long will they last?
- How can I manage the side effects?
- Will I have to stay in the hospital?

#### Quality of life

- What are the most important quality-of-life issues for me?
- What are the goals of the treatment?

## 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.

#### 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.” I am still here five years later. I just refuse to let ovarian cancer define who I am.”*



#### 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 well-being 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.**

## Side effects

You probably know quite a bit about ways to manage the side effects of ovarian cancer treatment. If so, some of this section may be more of a review for you. Each chemotherapy drug has potential side effects that can affect people differently.

You and your doctor may be able to structure your treatment plan to avoid or minimize certain side effects. Regular communication with your treatment team is the key to managing side effects. Discuss the potential side effects of each treatment you and your doctor are considering. Remember that chemotherapy affects everyone differently.

Once you start treatment, work closely with your doctor or nurse to ensure your side effects are managed and you are able to live well with your diagnosis. Pay close attention to how you feel and report any side effects to your doctor or nurse. The earlier they are aware of the problem, the sooner they can help you manage the problem.

Following are some of the most common chemotherapy side effects:

### 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.



## LUCIA

*“As a filmmaker and an ovarian cancer survivor who has experienced two recurrences, I have embraced living in the creative, inspiring spaces between the chaos. And I’ve learned to live fully and without regret.”*

### Mental health challenges

Cancer treatment can lead to feelings of depression, anxiety, or sadness. These emotions are normal, and support is available. If you’re struggling, talk to your healthcare team about resources like counseling, support groups, or medication. Taking care of your mental health is important for your overall well-being during treatment.

### 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, before treatment, some choose to use cooling caps (scalp hypothermia). 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.

## 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 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.

## CINDY

*"Cancer touches everyone's life in some way. I call this my journey of HOPE because from day one, regardless of the hardships, I discovered an inner strength fueled by my Faith and the outpouring of love, support, and prayers of family, friends, and so many caring people. I feel so fortunate to use my life to help others see the face of HOPE."*

Look Good Feel Better is a non-medical, brand-neutral program dedicated to improving the well-being of individuals in cancer treatment. Through complimentary workshops, the program empowers participants by teaching beauty and styling techniques to address the visible effects of cancer treatment, helping them face their diagnoses with greater confidence. By teaching patients how to look and feel like themselves again, Look Good Feel Better helps them to find some normalcy during a time that is by no means normal.

**For information, call 1-800-395-LOOK or go to [www.lookgoodfeelbetter.org](http://www.lookgoodfeelbetter.org).**

## 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.

## 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 booklet on living well after an ovarian cancer diagnosis.



## The importance of nutrition and exercise

### Nutrition

One of the most important things you can do for yourself as you undergo treatment for recurrent ovarian cancer is to eat healthily. But treatment may make you lose your appetite. During the course of your treatment, your doctor may refer you to a nutritionist. This specialist can help design a good nutrition plan that you can easily follow. It is recommended that this plan consists of 5 fruits and vegetables a day. (Note: Fresh fruits and vegetables should be avoided if you are neutropenic.) It is also suggested that you eat chicken and fish and avoid red meat.



- Maintain a well-balanced diet: If you feel nauseated, eat plain carbohydrate foods, such as toast, pretzels, crackers, oatmeal, noodles or white rice.
- Eat smaller, more frequent meals: Eat smaller portions more often throughout the day. If you have a decreased appetite, keep your favorite foods on hand to help you eat more.
- Snack between meals: Have a high-protein diet supplement or milkshake to add calories and nutrients.
- Plan meals: Decide your menus in advance and freeze extra meals to simplify your cooking schedule. If you often feel tired, buy foods that need little or no work to prepare.
- Make eating enjoyable: Dine with family or friends, play music, or set a tranquil mood with candles.

### Exercise

While it may be the last thing on your mind when you have cancer, exercise (if approved by your doctor) can help you gain energy, build and maintain strength, boost your immune system, and relax your mind. Even a small amount of exercise can be beneficial. Clear all exercise with your doctor before starting and discuss what type/level of exercise is appropriate for you. Consider low-impact activities. Walking, stretching, and yoga are gentle ways to get back into exercise, raise your heart rate, and regain strength.



### 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."*



## CHAPTER 4

# MENTAL AND EMOTIONAL HEALTH

Learning that your cancer has returned will stir up many emotions. You may feel angry, vulnerable, scared, or sad. It is important to be aware of your emotions and not keep them bottled up. Try to share your feelings with a family member or close friend. You may also find it helpful to spend time with a spiritual advisor or counselor to discuss your feelings.

Sometimes, as people focus on treating their cancer, they ignore their emotional well-being. Caring for your emotional well-being will ensure that you are able to focus and work with your doctor to devise the best possible treatment plan.

Not everyone has the same feelings and thoughts when cancer comes back. And everyone does not have the same challenges shared here, but many have these concerns.

### Recognizing when you are stressed

Dealing with the recurrence of a serious illness like ovarian cancer is extremely stressful. Everyone experiences stress differently, but some common responses to stress include headaches, jaw clenching, teeth grinding, neck or backache, dizziness, pain, heartburn, dry mouth, difficulty concentrating and making decisions, increased or decreased appetite, frequent crying spells, frustration, and irritability.

Learn to recognize signs of stress in yourself, and contact your healthcare professional if you experience the following on a regular basis:

- Denial about the disease and its effect on you and your family
- Anger directed at your loved ones
- Social withdrawal from friends and activities that once brought you pleasure
- Anxiety about facing each day and the future
- Depression and feeling unable to cope
- Exhaustion which makes it impossible to complete necessary tasks of the day
- Sleeplessness caused by constant concern and worry
- Lack of concentration, making it difficult to perform usual daily tasks

### Managing anxiety

Anxiety can happen to anyone, but women facing recurrent ovarian cancer may get anxious more easily than others. Anxiety and fear are common and normal feelings when coping with a life-threatening illness.

- Some signs of anxiety:
- Feeling uneasy and tense
- Feeling of restlessness, uncertainty, and dread
- Sweating a lot
- Having a rapid heart rate or feeling your heart pounding in your chest
- Having a knot in your stomach

In addition, some people experience shakiness or have difficulty falling asleep. Sometimes, individuals become overly fearful and no longer cope well with day-to-day life.

### Stress-reducing activities

- Breathing exercises or meditation
- Getting a massage
- Listening to relaxing music
- Taking a drive or spending time in nature
- Watching a funny movie or TV show
- Playing with your dog or cat (or any pet)
- Taking a class
- Crafting (knitting, painting, etc.)
- Exercising or gentle stretching
- Taking up a new hobby

Let your healthcare team know if you experience any of these symptoms for more than two weeks. Medication and/or counseling can be very effective in treating depression and anxiety. Without treatment, these can interfere with your ability to make decisions about treatment. Equally as important, if untreated, these can interfere with your ability to enjoy your family, friends, and the activities that bring you happiness.

#### SANDRA

*“Originally diagnosed with Stage IIIC ovarian cancer, I was told I would live three to four years. When cancer returned four years later, my thought was, “Well, they must have been right.” Seven years after my recurrence, I am not only here but thriving. Ovarian cancer doesn’t define me; it’s a part of my life, but I refuse to let it control me. Never give up, fight the good fight; you never know what lies ahead.”*

## Ways to cope

No two people experience anxiety in the same way. Here are some tips other people have found helpful:

- Try to identify what triggers your anxiety.
- List coping strategies that have helped in the past.
- Talk with others about your anxiety. Consider attending a support group.
- Increase pleasurable distracting activities.
- Use relaxation techniques, such as controlled breathing or guided imagery (picture a pleasant scene in your mind).
- Be around others as much as possible if this is relaxing.
- Use prayer or other types of spiritual support, such as meditation.
- Talk with your doctor or nurse about prescribing medicine to help reduce your anxiety.
- Express feelings and concerns to others.
- Limit your caffeine by decreasing your intake of coffee, tea, cola, highly caffeinated beverages, and chocolate.
- Consider asking your doctor for a counseling referral.

## Talking with others about your anxiety

- Be open and honest about your feelings and concerns with your family members.
- Try to describe your feelings when you're experiencing them (racing thoughts, lump in your throat, nausea, shortness of breath, or being dizzy).
- Ask your family members and friends how your anxiety is affecting them.

## Managing depression and sadness

Understandably, you may feel sad if you have to deal with recurrent ovarian cancer. Depression is a sadness that happens in response to an event or due to changes in your body chemistry. It is a sadness that is greater than normal, lasts two weeks or more, and greatly impacts your daily life.

## Recognizing depression and sadness

Many describe depression as the darkest time of their life. Many report crying for long periods of time or many times each day, as well as problems with sleep (either sleeping all day or not getting enough sleep). Others describe problems with eating (too much or not enough), feeling hopeless, helpless, worthless, or even feeling like they want to hurt themselves. People may have trouble experiencing any pleasure or interest in daily life, and they may not want to talk to family or friends.

## The causes of depression and sadness

Depression can occur as a result of specific events, such as the diagnosis of recurrent ovarian cancer. It also can be caused by medications, fatigue, or from chemical changes in the brain. Generally, most people can cope with general, short-term feelings of depression. But if it lasts more than two weeks, talk to your doctor for possible counseling or medication.

Family members and friends can help. You can ask them to:

- Stay with you (if you live alone) so that you are not by yourself.
- Talk with you about what you're going through.
- Do fun things with you.
- Sit with you during difficult times. Sometimes, just having someone there with you is enough.
- Help you with your daily needs until you are able to care for these on your own.
- Help you with relaxation exercises.
- Help you with situations that you find stressful, such as going to your doctor visits or helping with household chores.
- Notify your doctor or nurse when needed.

## Timely tips

Every person uses different approaches when they are depressed and sad. Following are tips other people have found helpful:

- Try controlled breathing and relaxation exercises; these help release mood-enhancing substances from the brain.
- Express your feelings through journal writing or creative expression (dance, cooking, exercise, painting, or music).
- Avoid alcohol consumption; it can make you feel more depressed.
- Try to get enough sleep at night; avoid napping during the day.
- Go outdoors and walk in natural settings, such as gardens or parks.
- Try meditation or massage.
- Try to identify something that brings you pleasure every day.
- Be with other people as much as possible, if this helps you relax.
- Participate in regular, routine exercise (for example, walking for 20 minutes, 3-5 times per week). Exercise has been shown to improve mood and well-being.
- Make an appointment with your doctor and tell him/her exactly how you feel and that you need help. Make a list of all the medications you take; show this to your doctor or nurse. Some medicines may have to be stopped or changed.
- Join a support group.
- Make an appointment with a counselor, spiritual advisor, or psychologist.
- If medicines have been ordered for your depression, take them as directed.

## Getting support and support groups

An ovarian cancer diagnosis can often leave you feeling isolated. But you are never alone. 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. They can also 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.

If you think you might be interested in a support group, the NOCC hosts many different groups. You can also ask the healthcare team at your cancer care center, hospital, or oncology group if they offer one. Or, call a nearby cancer center or university hospital and ask if there is a support group in your community.



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).



### Teal Hearts Network - NOCC Survivor Peer-to-Peer Support Group 1.888.OVARIAN

[nocc@ovarian.org](mailto:nocc@ovarian.org) | [ovarian.org](http://ovarian.org)  
Join an NOCC 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 - NOCC 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.

If you or someone you know is in need of immediate help regarding suicidal thoughts, it's crucial to reach out to local emergency services or a mental health professional.

### Call the National Suicide Prevention Lifeline - Call 988

They provide free and confidential support for people in distress, prevention and crisis resources for you or your loved ones, and best practices for professionals 24/7.

## End-of-life concerns

End-of-life concerns can be a deeply personal and emotional topic for individuals facing recurrent ovarian cancer. It's natural to feel a mix of emotions, including fear, sadness, and uncertainty, as you consider what the future holds. Discussions about end-of-life care are essential for ensuring that your wishes are respected and that you receive the care that aligns with your values and priorities. This is a time to explore your goals, whether they focus on comfort, time with loved ones, or personal achievements. It's also important to communicate openly with your healthcare team, family, and friends about your desires, including decisions about treatments, palliative care, and advanced directives.



For more detailed information about end-of-life concerns, read our booklet on living well after an ovarian cancer diagnosis, with tips for enhancing well-being and managing different challenges.



## CHAPTER 5 RESOURCES

The following resources offer credible programs and information that will be helpful to you as you seek information and support. Keep in mind—especially as you seek information on the Internet—not all sites offer scientifically validated or accurate information, and some fringe 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, 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

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

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

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

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

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

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

**LIVESTRONG**  
855-220-7777  
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

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

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

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

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

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

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

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

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

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

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

### ASHLEY

*"The best medicine is smiling and keeping a positive attitude. Support groups really do help you connect. Friends and family play a huge role, and keeping them close during this time will help you get through the tough times. Remember that no one fights alone. We are teal sisters, and we have a strong bond that no one can break!"*

## 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 may be able to 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.

### MEREDITH

*"The journey has many twists and turns. Surround yourself with people that help you rise. Don't let cancer define you, and be kind to your soul. Raise your voice. Advocate for yourself and future generations. Most importantly - know you are not alone."*

## 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.

**Germline Genetic Testing:** This type of testing looks at the DNA you were born with, which you inherited from your parents.

**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.

**Invade:** 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, 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.

**Palliative care:** Supportive care aimed at improving quality of life by managing symptoms and treatment side effects.

**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.

**Somatic Genetic Testing:** This test checks for genetic changes that happen in your body's cells over time, not the ones you were born with.

**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 can help you through this time. We know that the information may seem overwhelming at first. We know it is difficult to have to go through treatment for cancer again.

We hope that the knowledge and understanding you may have gained by reading this guide gives you the strength to face the challenges that come with recurrent ovarian cancer. Treatment options for those with ovarian cancer are undergoing a revolution. There are hundreds of drugs currently being studied to improve treatment outcomes.

This guide provides a lot of information, and we hope it is helpful as a reference. But remember, this guide is only a place to start. You must be your own best health advocate. If you have a question about your treatment, seek a second or even a third opinion.

As always, if you have any questions, feel free to contact us at 1-888-OVARIAN (682-7426) or visit our website, [www.ovarian.org](http://www.ovarian.org). If, for any reason, we are unable to answer your question, we will direct you to someone who can.

In the spirit of care and support, we encourage you to be kind to yourself and treasure every day by living life to the fullest.



## 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:  
<https://ovarian.org/get-involved/nocc-communities>





For more information, please contact us at:

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