About the National Ovarian Cancer Coalition (NOCC)

Since its inception in 1995, the National Ovarian Cancer Coalition (NOCC) has been committed to raising awareness of ovarian cancer in communities across the country through education and support. As the first and only national ovarian cancer organization with a network of local chapters located throughout the United States, NOCC has established itself as the leading advocate for patients and families coping with ovarian cancer. NOCC works to advance its mission through national awareness and survivorship programs, a comprehensive website, a toll-free information line, peer support, professional education, and publications like this one.

NOCC’s national programs include:
• The Take Early Action & Live (teal) initiative provides education and increases awareness of ovarian cancer.
• Faces of Hope provides up-to-date information, hope, and support to women with ovarian cancer, their families, friends and loved ones.
• The Run/Walk to Break the Silence on Ovarian Cancer raises awareness, celebrates survivors, and remembers those lost to the disease.

NOCC also works to promote ovarian cancer research. For more information about NOCC, visit www.ovarian.org or call 1-888-OVARIAN (1-888-682-7426).
A Resource Guide for Newly Diagnosed Women

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Receiving a diagnosis of ovarian cancer from your doctor is, without a doubt, 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 and your family through your journey. Many of us are ovarian cancer survivors and we are here to provide you with information, compassion, and encouragement.

The Ovarian Cancer Resource Guide has been designed to empower you with up-to-the-moment, expert information that will answer your commonly asked questions. The guide has been reviewed by ovarian cancer experts and is divided into four sections.

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

Receiving a cancer diagnosis is life-changing, and you and your loved ones may be experiencing shock and disbelief right now. It’s important to realize, however, that many women with ovarian cancer do gradually adjust, and in fact go on to live full and rewarding lives despite their cancer diagnosis.

Remember, since treatments and research are always evolving, check in with us often for the latest information. Cancer is a difficult challenge, but it is met most easily with good information and support. You always can visit our website www.ovarian.org, call 1-888-OVARIAN, or contact your local NOCC Chapter.
Understanding Ovarian Cancer

• What Is Ovarian Cancer?
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Cancer Basics

Ovarian cancer is a disease in which cancerous cells are found in the tissues of the ovary. You have two small, almond-size ovaries located in your lower abdomen, one on each side of the uterus (the hollow, pear-shaped organ where a fetus grows). Every month, during a menstrual cycle, the ovaries release an egg (ova) that travels through the fallopian tubes into the uterus and has the potential to become fertilized. The ovaries are also the main source of the female reproductive hormones, estrogen and progesterone, which control sexual development and regulate the menstrual cycle. When you go through menopause, the ovaries stop releasing eggs and produce fewer hormones.

Normally, cells in your body grow and divide to form new cells to replace worn out or dying ones. But sometimes this process goes awry. New cells begin to grow uncontrollably in part of your body (in this case the ovary) and old cells do not die when they should. These extra cells can form a mass of tissue called a tumor or growth. The tumors may be benign (non-cancerous) or malignant (cancerous).

Ovarian cancer cells sometimes can travel to other parts of the body where they begin to grow and replace normal tissue. The cells can invade nearby organs such as the fallopian tubes or the other ovary. They can also spread through the bloodstream or lymph vessels of your body. When cancer cells break away from the original (primary) tumor and travel through the body, another tumor may form. This process is called metastasis. The new tumor is the same type as the original tumor. For instance, if ovarian cancer spreads to the liver it is known as metastatic ovarian cancer, not liver cancer. Cancer cells that spread to the ovary from other organ sites such as the breast are not considered ovarian cancer.

What Caused Your Ovarian Cancer?

You may be asking yourself why you got ovarian cancer and whether you could have done something to avoid it. Unfortunately, researchers still aren’t sure of the exact cause of the disease. There are factors that increase your risk for developing it, such as having a family history of ovarian, breast, or colorectal cancer, but risk factors don’t really tell you anything. 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.

Studies show that inheriting a defect in the BRCA1 (breast cancer 1) or BRCA2 (breast cancer 2) gene can increase your risk of developing ovarian and breast cancer. Women with the BRCA1 mutation have a 50 to 85 percent risk of developing breast cancer by age 70, a 40 to 60 percent risk of ovarian cancer by age 85, and an increased risk of colon cancer. Individuals with the BRCA2 gene are also at increased risk, however the risk is less than those with the BRCA1 gene.

Since you’ve already been diagnosed, you might consider consulting with a genetic counselor to determine whether you have the marker and therefore run a higher risk of breast cancer. A high-risk determination may lead you to have more frequent screenings, such as mammograms, ultrasounds, and physician-assisted examinations. You might also want to consider genetic testing since you can pass the gene mutation to your children. Men can also be carriers of the BRCA1 and BRCA2 genes and can therefore pass the genes down to their children.

Some experts recommend tests for women who are of Ashkenazi Jewish descent (Jews whose ancestors came from Eastern Europe) and who have a first-de-
Types of Ovarian Tumors

There are more than 30 different types of ovarian cancer, classified by the type of cell from which they originate. The three most common types of ovarian cancer are:

**Epithelial tumors**: About 90 percent of ovarian cancers are of this type. The tumors originate in the epithelium, which is the tissue that covers the outside surface of the ovary. The risk of epithelial ovarian cancer increases as you age and occurs mostly in women over 60, but can develop at any age. The majority of women with epithelial cancer are not diagnosed until the disease is more advanced.

There are some ovarian epithelial tumors whose appearance under the microscope exhibit some characteristics of malignancy, but appear to still be early enough in their development to be treated successfully. These are called borderline tumors or tumors of low malignant potential (LMP tumors).

**Germ cell tumors**: These tumors originate in the germ cells (cells that produce individual eggs). This type of ovarian cancer is rare (accounting for one in 20 ovarian tumors) and mostly affects teenagers and women in their 20s. Many germ cell tumors are non-cancerous.

**Stromal tumors**: These tumors develop in the supporting connective tissue that holds the ovary together. The hormones estrogen and progesterone are made in the stromal cells. These tumors typically occur in women aged 40-60, but they are relatively rare.

Stage I means your cancer is only in the ovaries. Stage I is divided into three groups:

- **Stage IA**: The cancer is completely inside one ovary.
- **Stage IB**: The cancer is completely inside both ovaries.
- **Stage IC**: The cancer is classified as either stage IA or IB and one or more of the following are present: There is some cancer on the surface of one or both ovaries; there are malignant cells in fluid taken from inside your abdomen during surgery; or the ovary has broken before or during surgery.

Stage II means your cancer involves one or both ovaries and has spread to the area circled by your hip bones (the pelvis). It can be classified as:

- **Stage IIA**: The cancer has spread into the fallopian tubes or uterus, or both.
- **Stage IIB**: The cancer has spread to other pelvic organs such as the bladder or rectum.
- **Stage IIC**: The tumor is classified as either stage IIA or IIB and one or more of the following exist: There are malignant cells in fluid taken from inside your abdomen and the cancer has grown into other tissues in the pelvis.

Did You Know?

The Pap test does not detect ovarian cancer. It determines cancer of the cervix.

For more information on genetic testing or for help finding a health care professional trained in genetics, contact the National Cancer Institute’s Cancer Information Service (CIS) at 1-800-4-CANCER (1-800-422-6237).
Stage III cancer of the ovary means the 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. Most women with ovarian cancer are diagnosed with Stage III or advanced-stage cancer. This is because the symptoms of ovarian cancer (particularly in the early stages) often are not acute or intense, and don’t present any obvious signs. In most cases, ovarian cancer is not detected during routine pelvic exams, unless the doctor notes that the ovary is enlarged.

- **Stage IIIA**: Cancer cells are in the lining of the abdomen but are too small to see without a microscope. Cancer has not spread to the lymph nodes.
- **Stage IIIB**: The tumor is in one or both ovaries and deposits of cancer in the abdomen are large enough for the surgeon to see, but do not exceed 2 centimeters in diameter. The cancer has not spread to the lymph nodes.
- **Stage IIIC**: The tumor is on one or both ovaries and one or both of the following is present: The deposits of cancer exceed 2 centimeters in diameter and are found in the abdomen; and/or cancer has spread to the lymph nodes in the upper abdomen, groin, or beyond the uterus.

Stage IV is the most advanced stage of ovarian cancer in which the cancer growth involves one or both of the ovaries and the cancer has spread to other organs in the body such as the liver and lungs.

**Ovarian Cancer Treatment**

After your diagnosis, your doctor will develop your customized treatment plan. You should always discuss your treatment options with a physician because the best and most appropriate treatment will be different based on the stage of the disease, your age, your desire to have children (preserve fertility), and the overall condition of your health. The three main treatment types for ovarian cancer are:

- **Surgery**: Once ovarian cancer is suspected, surgery to remove the cancerous growth is performed. Your doctor may refer you to a gynecologic oncologist, a surgeon who specializes in treating ovarian cancer.

**Chemotherapy**: Chemotherapy (often referred to as “chemo”) involves using chemicals (medications) that travel through the bloodstream to destroy cancer cells or stop them from growing both in and outside the ovaries. Chemotherapy is used in the majority of cases as a follow-up to surgery. However chemotherapy is sometimes used before surgery (also called neoadjuvant chemotherapy) with the aim of shrinking a tumor and making it easier to remove all of the cancer.

**Radiation Therapy**: Radiotherapy, also known as radiation therapy, uses high-energy X-rays to kill cancer cells and shrink tumors. It is not commonly used in the treatment of ovarian cancer.
Choosing Your Healthcare Team
Finding a Gynecologic Oncologist

If you are facing surgery for a suspicious ovarian mass or if you've already been operated on by a gynecologist or general surgeon, it's not too late for you to seek the opinion of a 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, as well as decreasing rates of recurrence. Gynecologic oncologists not only are skilled surgeons but they are 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 fewer than 1,000 board-certified gynecologic oncologists in the U.S. Those women 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 women with ovarian cancer include gynecologists and medical oncologists.

Your first step in finding a gynecologic oncologist is contacting your insurance provider. Ask what oncologists are in the network and if any are gynecologic oncologists. Also, ask your referring physician for names of any gynecologic oncologists in your community. You can also find such a specialist by searching the Foundation for Women’s Cancer national list of gynecologic oncologists at www.foundationforwomenscancer.org or by calling 1-800-444-4441.

Questions to Consider When Choosing Your Doctor
• Is your doctor a gynecologic oncologist?
• Is he/she experienced in treating your kind of ovarian cancer?
• Does the doctor accept your insurance?
• Do you find it easy to communicate freely with him/her?
• Is the doctor's staff nice and helpful?
• Does the doctor have a good reputation among other doctors and patients?
• Does he/she administer chemotherapy?
• Does the doctor (or someone from the office) return your calls quickly?

Should I Get a Second Opinion?
Once your doctor tells you your diagnosis and treatment plan, you may want to get another doctor’s advice before you begin treatment. This is known as getting a second opinion. Getting a second opinion is a commonly accepted practice, yet many people do not seek one because they are afraid they will offend their current physician or because they just don’t have the energy it takes to find and see another doctor.

You have nothing to lose by obtaining a second opinion—and everything to gain. If possible, get a second opinion before you begin treatment. Get a copy of all test results, lab and pathology reports, and all records regarding your conditions as soon as you can. 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 ultimately make a better-informed decision about your course of treatment.

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 in greater concentration in ovarian cancer cells than in other cells. While your CA-125 is an important test, it is not considered a useful screening tool because some non-cancerous diseases of the ovaries also increase CA-125 levels, and some ovarian cancers may not produce enough CA-125 levels to cause a positive test. However, the CA-125 helps in monitoring women 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. Recently a HE4 blood test has also been used to monitor recurrent or progressive disease in women with epithelial ovarian cancer.

Questions to Ask the Second Doctor
• Do you agree with the original 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 ovarian cancer, your mind may race with questions, worries, and fears. You may worry about changes in your body, the effect your illness will have on family and friends, and whether you will survive the disease or treatment. Do not hesitate to communicate with your healthcare team. They are there to help you. Many women 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 women who have cancer.

Also, ask your health care team what hospital services are available for women with your disease. There may be support groups, financial or transportation assistance, information about nutrition and exercise, or other programs. But the information might not be offered to you unless you ask for it. You are your own best advocate. Communicate openly and frequently with your team, your family, and your friends.

Getting the Most Out of Your Doctor Visits

The reality is, even the most caring and communicative doctors have hectic schedules and often have limited time to spend with their patients during each visit. By preparing in advance, you can 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 a second pair of ears. Sometimes, it can be difficult to concentrate and remember information when you visit the doctor. Consider taking a family member or friend with you to your appointments to help you write down what the doctor says. You also might find it helpful to bring along a tape recorder. Since not all doctors are comfortable with this, ask if it's okay.
- Request easier explanations. If the doctor answers in technical language you do not understand, ask him or her 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 stupid questions. This is your appointment, your personal time to consult with your physician. Be respectful of your doctor's schedule, but be sure to 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.

SOME QUESTIONS TO ASK YOUR DOCTOR

- How far has my ovarian cancer spread?
- What is the stage of my cancer and what does that mean?
- Has all my cancer been removed?
- What are my treatment options? If chemotherapy, what chemotherapy drugs do you recommend?
- How many treatments will I need? How frequent will they be?
- What will the cost 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?
- How often should I have CA125 assessments?
- 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?
Introduction to Clinical Trials
You’ve probably heard of clinical trials, but may not be sure what they are, exactly. Basically, a clinical trial is a research study of how a new medicine or treatment works in people. If you choose to participate in a clinical trial you will not be treated like a guinea pig. A new medicine or treatment reaches a point where it can be evaluated in a clinical trial only after it proves successful in lab studies and then in animals. Those who run the trials are basically trying to offer you a promising treatment option.

What are the Phases of Clinical Trials?
All clinical trials are conducted in phases. At each phase, the trials have a different purpose.

- **In Phase I trials**, researchers test an experimental 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 experimental drug or treatment is given to a larger group of people (100-300) to test its efficacy and to further evaluate its safety. Sometimes participants are assigned to one of two treatment groups. The groups may get different doses or get the treatment in different ways, much like what is done in phase III trials. About one-third of experimental drugs successfully complete both Phase I and Phase II studies.
- **In Phase III trials**, the experimental 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. Participants are often chosen at random (called randomization) to receive either a standard treatment or the new treatment. Whenever possible, neither the doctor or the patient knows which treatment the participant is receiving. Once this phase is complete, a pharmaceutical company can request U.S. Food and Drug Administration (FDA) approval for marketing the drug.
- **In Phase IV trials**, post-marketing studies are conducted after the drug has been approved for consumer sale. Pharmaceutical companies determine additional information including: the drug’s long-term effectiveness, how it compares to other drugs already on the market, and its cost-effectiveness. Phase IV studies can result in a drug being taken off the market or restrictions placed on its use.

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 and is a decision that you should make 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 hit the market; you can obtain expert medical care at leading health care facilities during the trial; and you can withdraw from a clinical trial at any time. For many women 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; and 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.

Some questions to ask:
- What is the purpose of the study?
- Who is conducting the trial?
- How many patients will be involved?
- What is likely to 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?

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.

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.

**National Ovarian Cancer Coalition, Inc.**
1-888-OVARIAN (1-888-682-7426)
www.ovarian.org

**Cancer Trials Support Unit**
1-888-823-5923
www.ctsu.org
The Cancer Trials Support Unit is a project sponsored by the National Cancer Institute (NCI) to make NCI-supported Phase III cancer treatment trials available to physicians nationwide.

**ClinicalTrials.gov**
A service of the NIH, this is a registry of federally and privately supported clinical trials conducted in the U.S. and around the world.

**Coalition of Cancer Cooperative Groups**
1-877-227-8451
www.cancertrialshelp.org
The Coalition of Cancer Cooperative Groups is composed of cancer clinical trial specialists and offers a variety of programs and information for cancer patients, healthcare providers, and patient advocates. These programs are designed to increase awareness and participation in clinical trials.

**EmergingMed**
1-877-601-8601
www.emergingmed.com
This site allows you to create a profile that can then be matched to clinical trials.

**National Cancer Institute Clinical Trials Referral Office**
1-888-NCI-1937 (1-888-624-1937)
http://ccr.nci.nih.gov/trials
This is the cancer-specific arm of the NIH; it offers comprehensive information about cancer clinical trials.
Complementary and Alternative Medicine

It’s natural to want to fight your ovarian cancer any way you can. In recent years, increasing numbers of Americans—including women with ovarian cancer—have been turning to complementary and alternative medicine (CAM) in pursuit of health and well being. CAM is a group of diverse practices and products that are used in conjunction with conventional medicine. As more and more major universities and healthcare facilities get involved with CAM research, the boundaries between CAM and conventional medicine are changing. Specific CAM therapies may, over time, become even more widely accepted in enhancing your fight against ovarian cancer.

There are countless complementary therapies, but many women with ovarian cancer have especially benefited from the following ones. You might want to speak with other women 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.

**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 some women with nausea, pain and other side effects of cancer treatment.

**Aromatherapy**: The use of 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 prior to 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 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. It is well documented that hope, belief, and faith positively influence health outcomes.

**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.

A Survivor’s Story

“Nothing prepared me for the day I heard the doctor say that I had ovarian cancer. The news hit me like a ton of bricks. My husband and I had not yet had children. That, coupled with medical bills and chemotherapy made the word “overwhelming” seem like a dramatic understatement. Well, here I am, about six years later, and I am completely healthy and cancer free. I have given birth to two beautiful children and am living life to the fullest. Cancer is a foe I would have never chosen to come up against, but I am learning to use the experience as a stepping stone as opposed to a stumbling block.”

—Kimberly, Pittsburgh, PA
Reiki: Reiki is a form of Japanese energy medicine in which a practitioner places his or her hands on or near the person receiving treatment, with the intent to transmit universal life energy and promote balance throughout the body.

Tai Chi: 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, contact the National Center for Complementary and Alternative Medicine (NCCAM), a federally funded center that supports research on complementary treatments, at http://nccam.nih.gov or call 1-888-644-6226. NCCAM and the National Library of Medicine (NLM) have partnered to create “CAM on PubMed.” It allows you to search for materials about CAM therapies in the NLM database: http://nccam.nih.gov/research/camonpubmed.

Differences Between Complementary, Alternative and Integrative Medicine

Many people are confused about the differences between “complementary,” “alternative,” and “integrative” medicine therapies. “Complementary medicine” refers to the use of CAM together with conventional medicine—for example, using acupuncture to help with the side effects of chemotherapy. “Alternative medicine” refers to the use of a treatment in place of conventional medicine. One example is using a special diet to treat cancer instead of a method that your oncologist suggests. “Integrative medicine,” also referred to as integrative oncology, is a total approach to care that combines both conventional and CAM treatments that show the most promise. For instance, some women learn to use meditation as a way to reduce stress during chemotherapy.

Insurance Issues

It’s important to have and keep good medical insurance since there are many expenses associated with managing cancer. Perhaps you have private insurance through an individual plan or an 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 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) for information and free publications regarding tax exemptions for cancer treatment expenses.

A Survivor’s Story

“My life has certainly changed after the cancer diagnosis. I am more conscious about my health. I never miss any of my doctor appointments. I live a healthier lifestyle and exercise on a regular basis. Every day I’m thankful to live one more day and I live everyday as if it were my last. My family is my inspiration. I want to see my grandchildren grow up. I am happy to be alive."
—Rosa, Mt. Laurel, NJ
Managing Your Treatment and Coping with Side Effects

Managing Your Treatment
and Coping With Side Effects

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  - Mouth Sores or Tender Gums
  - Constipation and Diarrhea
  - Nerve and Muscle Problems
  - Skin Irritation
  - Pain
  - Sexual Side Effects
  - Memory Problems
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.

Good communication with your healthcare team is essential as you plan your treatment schedule. If the team is aware of your preferences, they may be able to 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 for your healthcare team:

- What specific treatments will I receive and who will give me the treatment?
- How often will I be given chemotherapy drugs?
- 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 or stay with 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 chemotherapy?
- Does my health insurance pay for chemotherapy?

What to Expect From Your Treatment

If you and your doctor have chosen chemotherapy or radiation to fight your cancer, you need to prepare for the physical and mental challenges that treatment may bring.

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.

Instant Menopause

Some women with ovarian cancer have their ovaries surgically removed to treat the cancer. This surgery can cause pre-menopausal women to experience what is called “surgical” or “instant” menopause.

Detailed information about instant menopause can be found in NOCC’s booklet “Ovarian Cancer Sexuality and Intimacy.” This free booklet can be ordered by calling 1-888-OVARIAN.

Basics of Chemotherapy

Before you begin chemotherapy, it is important to understand how chemotherapy works. Chemotherapy is the treatment of cancer using chemicals designed to destroy cancer cells or stop them from growing. The goal of chemotherapy is to cure cancer, shrink tumors prior to surgery or radiation therapy, destroy cells that might have spread, or control tumor growth.
Chemotherapy is typically given at a cancer center, hospital or doctor's office. For stage II and up, six cycles of chemotherapy is the most common practice. This means receiving the drugs six times, about three weeks apart. However, this schedule might be modified a bit depending on which drugs are used. 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.

**Most chemotherapy drugs are given in one of the following ways:**

- By mouth—Swallowing a pill that your doctor prescribes.
- As a shot—Injected by a needle into a vein or muscle.
- Intravenous (IV)—A method of giving medicines or fluids using a needle or a thin tube (called a catheter) directly into a vein. It is also often given through a port, a small round disc made of plastic or metal that is placed under your skin in the upper chest, just below the collar bone. It allows for long-term delivery of chemotherapy without having to have multiple needle sticks.
- Intraperitoneal (IP)—In ovarian cancer, another way to administer chemotherapy is through a catheter placed in the peritoneal cavity (the area that contains organs such as your intestines, stomach, liver and ovaries).

**Coping With Side Effects**

Unfortunately, while chemotherapy kills the bad cancer cells in your body, it doesn’t make a distinction between cancerous cells and normal ones and can damage your healthy cells. This results in a variety of unwanted side effects which vary from person to person and one treatment to the next. The good news is that many side effects can be treated or managed.

Today there are drugs available to help prevent or reduce the side effects such as nausea and vomiting. There are also drugs to help minimize problems resulting from low blood counts, such as anemia or persistent infections. It will be important for you to tell your doctor and oncologist about any side effects you develop so they can prescribe any medication that’s needed.

Following is a description of some of the most typical side effects that may occur with common chemotherapy drugs and helpful tips to treat and relieve them.

**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 be suffering 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 a woman with cancer is anemia, a condition in which your body does not have enough red blood cells. Anemia happens when chemotherapy decreases the bone marrow’s ability to make red blood cells, resulting in a reduced amount of oxygen transported to all parts of the body. This causes chemotherapy patients to feel the symptoms of anemia—including extreme tiredness, headaches, heart palpitations, shortness of breath and difficulty sleeping.

A key sign of anemia in a person undergoing chemotherapy is when you feel so tired that you can’t do basic activities such as taking a shower, making the bed, cooking or climbing stairs. Chemotherapy-related anemia can be treated with iron replacement and transfusion.

**WHAT IS RADIATION THERAPY?**

Radiation therapy is an important treatment for many types of cancer including breast or thyroid cancer. However, it has 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. If radiation is being considered for your treatment, the NCI provides a booklet called “Radiation Therapy and You: A Guide to Self-Help During Cancer Treatment.” To view it go to [www.cancer.gov/publications](http://www.cancer.gov/publications).
Action Steps

Talk to your doctor about anemia: If you are feeling extremely tired, tell your doctor. He/she can do a simple blood test to determine if your fatigue is caused by anemia. If it is anemia, it can be treated and you can get back the energy and strength you need to fight your cancer.

Adjust your schedule: Adapt your activities based on your energy levels. Choose the activities you most want to do and let someone else help with the others.

Eat well and stay hydrated: Good nutrition will provide you with the calories and protein that your body needs. Calories will help keep your weight up and extra protein can help repair tissues that have been harmed by cancer treatment.

Allow time to sleep: Try to sleep at least eight hours each night. You might also want to take short naps to allow your body to get the rest it needs to recuperate from your cancer treatment.

Conserve energy: Only do activities that are most important to you. For instance, if you go to work, you might not clean house. Or you might use the dishwasher instead of washing dishes by hand.

Ask for help: Your family and friends want to help and are waiting for you to allow them to. They can pick up groceries, run errands, drive you to your doctor’s visits, or help with any other chores you feel too tired to do.

Nausea or Vomiting

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

Action Steps

Relax before treatments: Sometimes nerves or the thoughts of the treatment can trigger an upset stomach. Try meditating or imagining scenes that make you feel peaceful before your chemotherapy treatment. Or do quiet hobbies like knitting, listening to music, or reading.

Watch what you eat: Instead of three large meals each day, you might feel better with five or six small meals and snacks. Also, stay away from greasy, high-fat foods like potato chips, hamburgers, or fried foods.

Drink cool, clear liquids: Apple juice, tea, or ginger ale that has lost its fizz.

Rest after eating: Stay upright. Do not lie flat for at least one hour after eating.

Stay hydrated: If you vomit, sip clear, cool beverages or suck on ice cubes or popsicles.

Talk to your doctor: New medications can help reduce or even eliminate nausea and vomiting. These are called antiemetic or antinausea drugs. If one antinausea drug doesn’t work well for you, your doctor can prescribe a different one. Acupuncture may also help.

Hair Loss

For many women, 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 your eyebrows, eyelashes, arms and legs, pubic area, and underarms. Hair loss often starts two to three weeks after chemotherapy begins. You may lose it either a little bit at a time or in clumps. Losing your hair can be difficult, but the good news is that your hair will grow back. Hair usually starts to grow back in about a month or two after chemotherapy treatment ends.
Action Steps

Cut it off: Many women get a short “crew” cut in advance of treatment to minimize the psychological trauma when hair loss happens.

Consider a wig: Before you begin treatment, shop for a wig that matches your hair color, texture, and style. Take the wig to your stylist so it can be styled the way you prefer. Sometimes, insurance will cover wig costs. Be sure to check your policy and ask your doctor for a prescription for a “hair prosthesis.” Check out organizations such as “Look Good...Feel Better” (www.lookgoodfeelbetter.org) for valuable tips on hair loss, wig shopping and styling. If your insurance does not cover the cost of a wig, check with your hospital’s social work department about resources for free wigs in your community.

Protect your scalp: Hair loss sometimes starts with a “tingling” feeling as the first strands start to fall out. After hair loss, do whatever feels most comfortable for your scalp. You can cover your head with a hat, scarf or turban when outside. Or you can simply leave it bare.

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 what is called neutropenia—a deficiency of neutrophils—during your treatment, even minor infections can become a problem. This is why it is important during this period of vulnerability to take special precautions to protect yourself.

Action Steps

Avoid cuts and scrapes: Be careful when using knives, scissors, needles and shavers. If you accidentally cut yourself, clean the wound immediately with warm water, soap and an antiseptic.

Wash hands often: You and your family should wash hands before cooking and eating and after using the toilet, coughing, sneezing or touching animals. Carry hand sanitizer for times when you are not near soap and water.

Stay away from sick people: Try to avoid people with colds, coughs, flu, or other contagious illnesses.

Avoid crowds: Go shopping or do other activities at less-crowded times of day.

Trim your nails carefully: Avoid biting your nails or cutting your cuticles.

Take care of your skin: Don’t squeeze or scratch pimples. Dry yourself after a shower or bath by gently patting (not rubbing) your skin.

Get a new toothbrush: Use an extra-soft toothbrush that won’t hurt your gums. Talk with your doctor before using dental floss.

Be careful around your pets: Do not clean your cat’s litter box, pick up dog waste, or clean fish tanks or bird cages.

Talk with your doctor: There are drugs for neutropenia. Although they may cause bone pain, they prevent delays in your treatment or reductions in your chemotherapy dosages.

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 especially necessary when you are fighting cancer.

Eating food high in protein, vitamins, and calories is very important during chemotherapy treatments. You need to keep up your strength during treatment and optimize your immune system. During the course of your treatment, your doctor may refer you to a nutritionist experienced with cancer patients. This specialist can help design a good nutrition plan that you can follow easily.
**Action Steps**

- **Maintain a well-balanced diet:** Eat high-nutrient foods like cheese, lean meats, cereal, milk, and eggs. If you feel nauseated, eat plain, complex carbohydrate foods like crackers or toast.

- **Eat at regular times:** Set a routine in which you eat smaller portions, more often, throughout the day.

- **Liquid meals:** Drink milkshakes, smoothies, or soup if you do not like eating solid foods. These liquids can help provide the protein and other nutrients your body needs.

- **Use plastic forks and spoons:** Some types of chemo give you a metal taste in your mouth. Eating with plastic can help decrease the metal taste.

- **Plan meals:** Decide your menus in advance and freeze extra meals to simplify your cooking schedule.

**Mouth Sores or Tender Gums**

Chemotherapy drugs can affect the healthy lining of your mouth, throat, and tongue and can cause you to have 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 infection.

- **Action Steps**
  - **Keep your mouth moist:** Sip often from a bottle of water and suck on ice chips or sugar-free hard candy.
  - **Choose soft textures:** Moisten solid foods with gravy or cheese sauce.
  - **Rinse your mouth frequently:** Gargle with mild salt water to remove loose debris, especially after meals.
  - **Avoid irritating food and drink:** Don’t consume oranges and other citrus foods and avoid spicy, salty or acidic foods.

**Constipation and Diarrhea**

During your treatment you may experience difficulty passing stool (constipation) or loose stools (diarrhea). These changes in your bowel habits can be caused by your cancer treatment, changes in your diet, pain medication (constipation), and inactivity. If you experience severe stomach pain, cramping, or diarrhea for more than a day, call your doctor.

- **Action Steps** to avoid or alleviate constipation
  - **Drink plenty of fluids:** Non-caffeinated and warm fluids can be more helpful.
  - **Eat high-fiber foods:** Plant-based foods such as vegetables, fruits, beans, and certain grains add fiber to your diet.
  - **Move around as much as possible:** Take a walk or exercise (if your doctor approves) to stimulate bowel movements.
  - **Add a fiber laxative to your diet.**
  - **Talk to your doctor** before using suppositories (laxatives other than fiber, stool softeners or enemas): Taking the wrong treatment can make your condition worse. Some of these treatments should not be used when your white blood counts are low.

- **Action Steps** to avoid or control diarrhea
  - **Drink plenty of fluids:** Water, clear broth, ginger ale or sports drinks.
  - **Avoid caffeine:** Stay away from coffee, black tea, cola, and chocolate.
  - **Eat low-fiber foods:** High-fiber foods such as raw fruits and vegetables, whole wheat breads and cereals, or cooked, dried beans can make diarrhea worse. Eat low-fiber foods such as bananas, white toast, white rice, and potatoes.

**Did You Know?**

Cancer drugs can change the way food tastes to you. Many people on chemotherapy have a constant metallic taste in their mouth. To some, foods taste bitter and quite different than they once did. Remember, changes in taste are temporary, so try to continue eating to keep up your weight and energy level.
Use reduced-lactose products.

Call your doctor: Check with your doctor before you take antidiarrheal medications or if you have a fever, bloody stools or severe cramps.

Nerve and Muscle Problems
Chemotherapy sometimes can 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. It can make it difficult to pick things up and to use your hands for things like buttoning a shirt. If you experience these symptoms, talk to your doctor. He or she may decide to alter your chemotherapy drug or dosage to help reduce these symptoms.

Action Steps ➔
Wear sturdy, non-slip shoes: To prevent falls, do not walk in socks without shoes.
Be careful when bathing: Use nonslip mats in the shower and consider temporarily installing a shower chair.
Soak your hands and feet: Try to relieve burning by soaking your hands or feet in warm or cool (not icy) water depending on what feels best to you.
Move carefully: Don’t step too quickly and remember to use hand rails on stairs for balance. Also be careful getting in and out of cars.

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

Action Steps ➔
Protect the skin: Some chemotherapy drugs may make you more sensitive to the sun. You may need to completely avoid direct sunlight. If you are in the sun, use sun-screen lotion with an SPF (skin protection factor) of 15 or higher.
Stay clean and dry: Use mild, moisturizing soap when bathing, rinse and pat dry. Avoid using hot water when bathing to prevent skin irritation.
Avoid wearing scents: Perfumes and colognes often contain alcohol which can dry the skin.

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.

Action Steps ➔
Treat pain early: Talk with your doctor or nurse early—don’t wait until your pain is unbearable to treat it.
Stay on schedule: Follow your doctor’s guidelines for taking medication. Don’t “wait it out” until the pain gets worse.
Try complementary therapies: Meditation, aromatherapy, acupuncture, yoga and other methods may help alleviate your pain.

A Survivor’s Story
“I am a cancer researcher, and an ovarian cancer survivor since 2007. I had a thorough knowledge of ovarian cancer symptoms and stages and what therapies are out there but all this knowledge didn’t help very much in my journey through the process of survivorship. I had the same emotions and “why me” questions throughout the process. Knowledge is not enough. We must break the silence together. Good luck with your journey and a cancer-free life!”—Ramila, Warminster, PA
Talk with your family and friends—Let them know about your pain so they can help you. If you are very tired or in a lot of pain, they can call your doctor or nurse for you. Let your doctor know if your pain is worsening so he/she can develop a personal pain-management plan that may include strategies for short-term and long-term pain relief and for brief, severe flare-ups called breakthrough pain.

**Sexual Side Effects**

Don’t be surprised if, during your treatment, you are not 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, and pain, and changes in your body and appearance (e.g. hair and weight loss) also can reduce your libido.

Although you may not be interested in sex and may feel tempted to withdraw, it is important that you and your partner communicate, address each other’s fears, and stay connected. Be patient with yourself, only do what you are comfortable with, and trust that in time, as you feel better, you will feel sexual again.

**Action Steps**  
**Communicate:** Talk to your partner about your needs and limits, and address each other’s fears.  
**Explore non-sexual intimacy:** Hugging, cuddling, kissing, and holding hands can be a satisfying addition or alternative to sex.  
**Rest and plan:** Rest before and after sexual activity and plan sexual activity during times when you think you have the most energy.  
**Use lubricants:** Hormonal changes can result in your vagina being drier than usual. Water-soluble lubricants can help.  
**Talk to someone:** In some cases, it’s helpful for couples to speak to a counselor or therapist to help deal with emotional issues and sexual problems associated with your cancer treatment and recovery.

**Memory Problems**

Many women complain that during chemotherapy and afterwards they experience a mental cloudiness. Its cause isn’t known, but it is commonly called “chemo brain” or “chemo fog.” You have trouble thinking, 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.

**Action Steps**  
**Tell others:** Let your family, friends and healthcare team know what you are going through. You are not imagining a problem. Ask loved ones to help you with daily tasks.  
**Use a daily planner:** It’s best to keep track of appointments and schedules, “to do” lists, important dates, and notes. Keep these all in one place.  
**Exercise your brain:** Do word puzzles, take a class, or learn a new language. Get enough rest and sleep.  
**Don’t try to multitask:** Focus on one thing at a time.  
**Talk with your doctor:** If your memory and thinking problems are causing problems for you in your daily life, speak with your doctor. There may be ways for you to deal with such side effects.

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A Survivor’s Story

“Find a group of people who are doing something positive with their experiences with ovarian cancer. I’m doing what I can – plodding forward, trying to raise awareness about signs and symptoms of ovarian cancer, and supporting women and their loved ones. It’s the only thing I know how to do. No one in my family had ever had cancer. Even now, after four years, sometimes it doesn’t seem real and I wonder when it will really hit me.”  
—Nora, Austin, TX
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.

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

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

Benign: Non-cancerous.

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

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.

Chemotherapy: The treatment of cancer by chemicals (drugs) designed to destroy cancer cells or stop them from growing.

Clinical Trial: A type of research study that tests how well new drugs or treatments work in people. Also called a clinical study or research study.

CT or CAT Scan (Computerized Axial Tomography): A diagnostic procedure that combines an X-ray with a computer to produce highly-detailed cross-sectional, three-dimensional pictures of the entire body. These tests are generally 100 times more detailed than X-rays.

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.

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.

Gynecologic oncologist: A doctor who specializes 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.

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: 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 who specializes in cancer therapy and handles 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.

**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.

**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.

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

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

**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.

**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.

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**A Survivor’s Story**

“My healing has had challenges, but reading other survivor’s stories has helped me to cope. I can see the progress I have made and how truly blessed I have been.” —Angela, Taylor, MI
The following resources offer credible programs and information that will be helpful to you as you seek information and answers. 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, www.ovarian.org.

**General Cancer Information**

**American Cancer Society**  
1-800-ACS-2345 (1-800-227-2345)  
www.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 (formerly People Living With Cancer)**  
1-703-797-1914  
www.cancer.net  
Links all American Society of Clinical Oncology information and materials to help patients and families make informed health-care decisions.

**National Cancer Institute**  
1-800-4-CANCER (1-800-422-6237)  
www.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 Alternative Medicine**  
1-888-644-6226  
www.nccam.nih.gov  
The nation’s lead agency for scientific research into the diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine.

**National Coalition for Cancer Survivorship**  
1-888-650-9127  
www.canceradvocacy.org  
The oldest survivor-led advocacy group in the country. Provides information on cancer support, advocacy, and quality-of-life issues.

**Women’s Cancer-Specific Organizations**

**National Ovarian Cancer Coalition, Inc.**  
1-888-OVARIAN (1-888-682-7426)  
www.ovarian.org  
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.

**FORCE: Facing Our Risk of Cancer Empowered**  
866-288-RISK (1-866-288-7475)  
www.facingourrisk.org  
FORCE is a nonprofit organization for women who are at high risk of developing breast and ovarian cancers 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**  
1-800-444-4441  
www.foundationforwomenscancer.org  
The Foundation (formerly the Gynecologic Cancer Foundation) provides programs to benefit women who have, or who are at risk of developing a gynecologic cancer. These programs raise awareness of ways to prevent, detect, and treat gynecologic cancers while providing education and support.

**Ovarian Cancer National Alliance**  
202-331-1332  
www.ovariancancer.org  
OCNA works to increase public and professional understanding of ovarian cancer and advocates more effective diagnostics, treatments, and a cure. OCNA sponsors an annual advocacy conference for survivors and families.

**Ovarian Cancer Research Fund**  
1-800-873-9569  
www.ocrf.org  
OCRF is devoted to the formation of early diagnostic treatment programs and research toward ending ovarian cancer.

**Patient/Caregiver Support Organizations**

**Bright Pink**  
www.bebrightpink.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.**  
1-800-813-HOPE (1-800-813-4673)  
www.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
1-800-552-4366
www.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
202-659-9709
www.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
www.caringbridge.org
Provides free websites that connect people experiencing a significant health challenge to family and friends.

LIVESTRONG
1-855-220-7777
www.livestrong.org
Helps those with cancer and their loved ones live strong through education, advocacy, public health events, and research.

Look Good...Feel Better
1-800-395-LOOK
www.lookgoodfeelbetter.org
Look Good...Feel Better is a free, nonmedical, brand-neutral, national public service program to help women offset appearance-related changes from cancer treatment.

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

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

Patient Advocate Foundation
1-800-532-5274
www.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.

Planet Cancer
www.planetcancer.org
This is an online community for young adults with cancer.

SHARE
1-866-891-2392
www.sharecancersupport.org
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.

Travel & Housing Organizations

Air Charity Network
1-877-621-7177
www.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
1-800-ACS-2345 (1-800-227-2345)
www.cancer.org
The ACS Hope Lodges offer free housing to patients and their caregivers when having to travel out of town for treatment.

Hospital Hosts
www.hospitalhosts.com
This organization helps families find housing that’s appropriate, affordable, and close to any medical facility.

Joe’s House
1-877-JOEHOU (1-877-563-7468)
www.joeshouse.org
Joe’s House provides a nationwide online service to help patients and their families find lodging near treatment centers.

Lifeline Air Ambulance
1-800-492-5433
www.lifelineairambulance.com
Provides worldwide emergency and routine air ambulance services.

National Association of Hospital Hospitality Houses, Inc.
1-800-542-9730
www.nahhh.org
Offers accommodations to families and their loved ones receiving medical treatment away from home.

National Cancer Institute
Designated Cancer Centers
Upon receiving a diagnosis of ovarian cancer, many women do not know where to turn for treatment. One place to begin is the National Cancer Institute’s list of designated “cancer centers” and “comprehensive cancer centers.” In every case, a center must meet stringent requirements to attain the NCI designation. The NCI separates cancer centers into two categories:

Cancer Centers have a scientific agenda that is primarily focused on basic, population sciences, or clinical research, or any two of the three components.

Comprehensive Cancer Centers integrate research activities across three major areas: laboratory, clinical and population-based research. The centers are expected to recruit patients for clinical trials.

Following is a list of current NCI designated centers by state. Since telephone numbers and web addresses can change, for the latest list you can also visit www.nci.nih.gov and search for “cancer centers.”

ALABAMA
UAB Comprehensive Cancer Center
University of Alabama at Birmingham
Birmingham, Alabama
205-934-5077
www.3.ccc.uab.edu
(Comprehensive Cancer Center)
ARIZONA
Arizona Cancer Center
University of Arizona
Tucson, Arizona
520-626-7685
www.azcc.arizona.edu
(Comprehensive Cancer Center)

CALIFORNIA
Chao Family Comprehensive Cancer Center
University of California at Irvine
Orange, California
714-456-6310
www.ufch.uci.edu/cancer
(Comprehensive Cancer Center)

City of Hope Comprehensive Cancer Center
Beckman Research Institute
Duarte, California
626-256-HOPE (626-256-4673)
www.cityofhope.org
(Comprehensive Cancer Center)

Jonsson Comprehensive Cancer Center
University of California, Los Angeles
Los Angeles, California
310-825-5268
www.cancer.ucla.edu
(Comprehensive Cancer Center)

Moores UCSD Cancer Center
University of California, San Diego
La Jolla, California
858-822-1222
www.cancer.ucsd.edu/
(Comprehensive Cancer Center)

Salk Institute Cancer Center
Salk Institute
La Jolla, California
858-453-4100
www.salk.edu
(Cancer Center)

Sanford-Burnham Medical Research Institute
La Jolla, California
858-646-3100
www.sanfordburnham.org
(Cancer Center)

Stanford Cancer Institute
Stanford University
Stanford, California
650-736-1808
www.cancer.stanford.edu
(Cancer Center)

UC Davis Cancer Center
University of California, Davis
Sacramento, California
916-734-5800
www.ucdmc.ucdavis.edu/cancer
(Cancer Center)

UCSF Helen Diller Family Comprehensive Cancer Center
University of California, San Francisco
San Francisco, California
415-502-1710
www.cancer.ucsf.edu
(Comprehensive Cancer Center)

USC Norris Comprehensive Cancer Center
University of Southern California
Los Angeles, California
323-865-0816
www.ccnt.hsc.usc.edu
(Comprehensive Cancer Center)

COLORADO
University of Colorado Cancer Center
University of Colorado at Denver & Health Sciences Center
Aurora, Colorado
303-724-7135
www.uccc.info
(Comprehensive Cancer Center)

CONNECTICUT
Yale Cancer Center
Yale University School of Medicine
New Haven, Connecticut
203-785-4371
www.yalecancercenter.org
(Comprehensive Cancer Center)

DISTRICT OF COLUMBIA
Georgetown Lombardi Comprehensive Cancer Center
Georgetown University Medical Center
Washington, D.C.
202-687-2110
www.lombardi.georgetown.edu
(Comprehensive Cancer Center)

FLORIDA
H. Lee Moffitt Cancer Center & Research Institute
University of South Florida
Tampa, Florida
813-615-4261
www.moffitt.org
(Comprehensive Cancer Center)

GEORGIA
Winship Cancer Institute of Emory University
Atlanta, Georgia
404-778-5669
www.emoryhealthcare.org
(Cancer Center)

HAWAII
University of Hawaii Cancer Center
University of Hawaii at Manoa
Honolulu, Hawaii
808-586-3010
www.uhcancercenter.org
(Cancer Center)

ILLINOIS
Robert H. Lurie Comprehensive Cancer Center
Northwestern University
Chicago, Illinois
312-908-5250
www.cancer.northwestern.edu/home/index.cfm
(Comprehensive Cancer Center)

University of Chicago Comprehensive Cancer Center
Chicago, Illinois
773-702-6180
www.uccrc.uchicago.edu
(Comprehensive Cancer Center)

INDIANA
Indiana University Melvin and Bren Simon Cancer Center
Indianapolis, Indiana
317-278-0070
www.cancer.iu.edu
(Cancer Center)

Purdue University Center for Cancer Research
West Lafayette, Indiana
765-494-9129
www.cancerresearch.purdue.edu
(Cancer Center)

IOWA
Holden Comprehensive Cancer Center
The University of Iowa
Iowa City, Iowa
319-335-8620
www.uihealthcare.com/depts/cancercenter
(Comprehensive Cancer Center)

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Process Cyan
Process Cyan
Process Magenta
Process Magenta
Process Yellow
Process Yellow
Process Black
Process Black
MAINE
The Jackson Laboratory Cancer Center
Bar Harbor, Maine
207-288-6841
www.jax.org
(Cancer Center)

MARYLAND
Marlene and Stewart Greenbaum Cancer Center
University of Maryland
Baltimore, Maryland
410-328-5506
www.umgcc.org
(Cancer Center)

The Sidney Kimmel Comprehensive Cancer Center
at Johns Hopkins University
Baltimore, Maryland
410-955-8822
www.hopkinsmedicine.org/kimmel_cancer_center
(Comprehensive Cancer Center)

MASSACHUSETTS
Dana-Farber/Harvard Cancer Center
Dana-Farber Cancer Institute
Boston, Massachusetts
617-632-2100
www.dana-farber.org
(Comprehensive Cancer Center)

David H. Koch Institute for Integrative Cancer Research at MIT
Massachusetts Institute of Technology
Cambridge, Massachusetts
617-324-3533
www.ki.mit.edu
(Cancer Center)

MICHIGAN
The Barbara Ann Karmanos Cancer Institute
Wayne State University School of Medicine
Detroit, Michigan
313-576-8670
www.karmanos.org
(Comprehensive Cancer Center)

University of Michigan Comprehensive Cancer Center
University of Michigan
Ann Arbor, Michigan
734-936-1831
www.mcancer.org
(Comprehensive Cancer Center)

MINNESOTA
Masonic Cancer Center
University of Minnesota
Minneapolis, Minnesota
612-624-8484
www.cancer.umn.edu
(Comprehensive Cancer Center)

Mayo Clinic Cancer Center
Mayo Clinic Rochester
Rochester, Minnesota
507-266-4997
www.cancercenter.mayo.edu
(Comprehensive Cancer Center)

MISSOURI
Alvin J. Siteman Cancer Center
Washington University School of Medicine and Barnes-Jewish St. Louis, Missouri
314-362-8020
www.siteman.wustl.edu
(Comprehensive Cancer Center)

NEBRASKA
Eppley Cancer Center
University of Nebraska Medical Center
Omaha, Nebraska
402-559-4238
www.unmc.edu/cancercenter
(Cancer Center)

NEW HAMPSHIRE
Norris Cotton Cancer Center
Dartmouth-Hitchcock Medical Center
Lebanon, New Hampshire
603-653-8064
www.cancer.dartmouth.edu
(Comprehensive Cancer Center)

NEW JERSEY
The Cancer Institute of New Jersey
Robert Wood Johnson Medical School
New Brunswick, New Jersey
732-235-8064
www.cinj.org
(Comprehensive Cancer Center)

NEW MEXICO
University of New Mexico Cancer Research & Treatment Center
University of New Mexico
Albuquerque, New Mexico
505-272-5622
www.cancer.unm.edu
(Cancer Center)

NEW YORK
Albert Einstein Cancer Center
Albert Einstein College of Medicine
Bronx, New York
718-430-2302
www.einstein.yu.edu/cancercenter
(Cancer Center)

Cold Spring Harbor Laboratory Cancer Center
Cold Spring Harbor, New York
516-367-8383
www.cshl.edu/cancercenter
(Cancer Center)

Herbert Irving Comprehensive Cancer Center
College of Physicians & Surgeons
Columbia University
New York, New York
212-851-5273
www.hiccc.columbia.edu
(Comprehensive Cancer Center)

Memorial Sloan-Kettering Cancer Center
New York, New York
212-639-2000 or 800-525-2225
www.mskcc.org
(Comprehensive Cancer Center)

New York University Langone Medical Center
New York University Medical Center
New York, New York
212-263-3276
www.cancer.med.nyu.edu
(Cancer Center)

Roswell Park Cancer Institute
Buffalo, New York
716-845-5772
www.roswellpark.org
(Comprehensive Cancer Center)

NORTH CAROLINA
Duke Cancer Institute
Duke University Medical Center
Durham, North Carolina
919-684-3052
www.dukecancer.org
(Comprehensive Cancer Center)

UNC Lineberger Comprehensive Cancer Center
University of North Carolina at Chapel Hill
Chapel Hill, North Carolina
919-966-3036
www.cancer.med.unc.edu
(Comprehensive Cancer Center)
Wake Forest Comprehensive Cancer Center
Wake Forest University
Winston-Salem, North Carolina
336-716-7971
www.wakehealth.edu/
(Comprehensive Cancer Center)

University of Pittsburgh Cancer Institute
UPMC Cancer Pavilion
Pittsburgh, Pennsylvania
412-623-3205
www.upci.upmc.edu
(Comprehensive Cancer Center)

The Wistar Institute
Philadelphia, Pennsylvania
215-898-3926
www.wistar.org
(Cancer Center)

OHIO
Case Comprehensive Cancer Center
Case Western Reserve University
Cleveland, Ohio
216-844-8562
www.cancer.case.edu
(Comprehensive Cancer Center)

SOUTH CAROLINA
Hollings Cancer Center
Medical University of South Carolina
Charleston, South Carolina
843-792-8284
www.hcc.musc.edu
(Cancer Center)

TENNESSEE
St. Jude Children’s Research Hospital
Memphis, Tennessee
901-595-3982
www.stjude.org/cancercenter
(Comprehensive Cancer Center)

Vanderbilt-Ingram Cancer Center
Vanderbilt University
Nashville, Tennessee
615-936-1782
www.vicc.org
(Comprehensive Cancer Center)

TEXAS
Cancer Therapy & Research Center
University of Texas Health Science Center at San Antonio
San Antonio, Texas
210-450-1000
www.ctrc.net
(Cancer Center)

Dan L. Duncan Cancer Center
Baylor College of Medicine
Houston, Texas
713-798-1354
www.bcm.edu/cancercenter/
(Cancer Center)

M.D. Anderson Cancer Center
University of Texas
Houston, Texas
713-792-2121
www.mdanderson.org
(Comprehensive Cancer Center)

Harold C. Simmons Cancer Center
at University of Texas
Southwestern Medical Center
Dallas, Texas
214-645-4673
www.simmonscancercenter.org
(Cancer Center)

UTAH
Huntsman Cancer Institute
University of Utah
Salt Lake City, Utah
801-585-0303
www.huntsmancancer.org
(Cancer Center)

VIRGINIA
Massey Cancer Center
Virginia Commonwealth University
Richmond, Virginia
804-828-0450
www.massey.vcu.edu
(Cancer Center)

UVA Cancer Center
University of Virginia,
Health Sciences Center
Charlottesville, Virginia
434-243-6784
www.uvacancer.com
(Cancer Center)

WASHINGTON
Fred Hutchinson/University of Washington Cancer Consortium
Fred Hutchinson Cancer Research Center
Seattle, Washington
206-667-4305
www.fhccrc.org
(Comprehensive Cancer Center)

WISCONSIN
UW Paul P. Carbone Comprehensive Cancer Center
University of Wisconsin
Madison, Wisconsin
608-263-8610
www.cancer.wisc.edu
(Comprehensive Cancer Center)
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 women with ovarian cancer are undergoing a revolution. There are hundreds of drugs currently being studied to augment or replace current medications.

**You have to be your own best health advocate. If you have a question about your treatment, seek a second or even a third opinion.**

In the meantime, though, 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, as well as decreasing rates of recurrence.

Remember, NOCC and our local chapters are on your side and always here to help. We’re a click away at www.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.

With support and encouragement,

National Ovarian Cancer Coalition
“See every difficulty as a challenge, a stepping stone, and never be defeated by anything or anyone.” — Eileen Caddy
We’re here for you
If there’s anything we can do to help you deal with the challenges of ovarian cancer, please call 1-888-OVARIAN (1-888-682-7426) or 214-273-4200. To find your local NOCC chapter, go to our website at www.ovarian.org

National Ovarian Cancer Coalition
2501 Oak Lawn Avenue, Suite 435
Dallas, TX 75219
1-888-OVARIAN (1-888-682-7426) or 214-273-4200
www.ovarian.org

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