

FOR NEWLY
DIAGNOSED WOMEN



*“ a ribbon
forged from
hope ”*

TM



ABOUT THE NATIONAL OVARIAN CANCER COALITION®

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, the NOCC has established itself as the leading advocate for patients and families coping with ovarian cancer. The 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.

The 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.
- *Together in TEAL® - Ending Ovarian Cancer* raises awareness, celebrates survivors, and remembers those lost to the disease.
- NOCC *CancerConnect* provides an online, HIPAA compliant platform to find peer-to-peer support, share experiences, and build community.
- The NOCC *Research in Action®* initiative provides critical funding to help support the progress of new treatment, and ultimately a cure, while supporting research initiatives such as clinical trials that save and extend lives today.

For more information about the NOCC, visit ovarian.org or call 1-888-OVARIAN (1-888-682-7426).



THE JOURNEY BEGINS

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, your family, and caregivers throughout 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 for newly-diagnosed women 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 ovarian.org, call 1-888-OVARIAN, or contact your local NOCC Chapter.

With support and encouragement,

NATIONAL OVARIAN CANCER COALITION



TABLE OF CONTENTS

CHAPTER 1 UNDERSTANDING OVARIAN CANCER 6

What Is Ovarian Cancer? 6	Should I Get a Second Opinion? 13
What Caused Your Ovarian Cancer? 6	Communicating with Your Healthcare Team 13
Types of Ovarian Tumors 7	Getting the Most Out of Your Doctor Visits 14
The Stages of Ovarian Cancer 8	Introduction to Clinical Trials 14
Ovarian Cancer Treatment 11	Complementary and Alternative Medicine 18
Questions to Consider When Choosing Your Doctor 11	Insurance Issues 20
Choosing Your Healthcare Team 12	
Finding a Gynecologic Oncologist 12	

CHAPTER 2 MANAGING YOUR TREATMENTS AND COPING WITH SIDE EFFECTS 22

Managing Treatment 23	Loss of Appetite and Taste Changes 28
What to Expect From Your Treatment 23	Mouth Sores or Tender Gums 29
Instant Menopause 24	Constipation and Diarrhea 30
Basics of Chemotherapy 24	Nerve and Muscle Problems 31
Coping with Side Effects 24	Skin Irritation 31
Fatigue and Anemia 25	Pain 31
Nausea or Vomiting 26	Sexual Side Effects 32
Hair Loss 27	Memory Problems 33
Infection 28	

CHAPTER 3 GLOSSARY OF CANCER TERMS 34

CHAPTER 4 RESOURCES 38

UNDERSTANDING OVARIAN CANCER

- **What Is Ovarian Cancer?**
- **Types of Ovarian Tumors**
- **What Caused Your Ovarian Cancer?**
- **The Stages of Ovarian Cancer**
- **Choosing Your Healthcare Team**
- **Finding a Gynecologic Oncologist**
- **Questions to Consider When Choosing Your Doctor**
- **Should I Get a Second Opinion?**
- **Communicating with Your Healthcare Team**
- **Getting the Most Out of Your Doctor Visits**
- **Introduction to Clinical Trials**
- **Complementary and Alternative Medicine**
- **Insurance Issues**

WHAT IS OVARIAN CANCER

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 can sometimes 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?

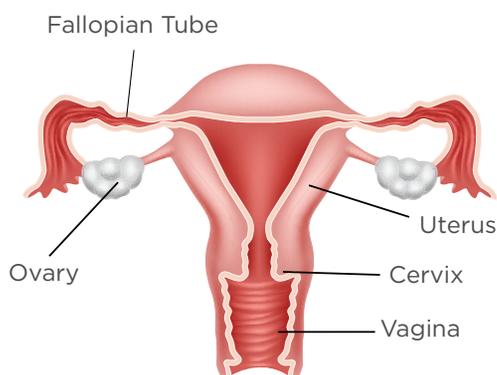
You may be asking yourself why you got ovarian cancer and whether you could have done something to avoid it. Unfortunately, researchers still aren't sure of the exact cause of the disease. There are factors that increase your risk for developing it, such as having a family history of ovarian, breast,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

DID YOU KNOW?

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

The Female Reproductive System



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 noncancerous.

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.

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-degree relative (parents, sisters, children) with breast or ovarian cancer, or two second-degree relatives (aunts, nieces, grandparents) on the same side of the family with breast or ovarian cancer. Even if you are not Jewish, the test is recommended if there's a history of these diseases, fallopian tube or peritoneal cancer in your family. But keep in mind that not everyone who inherits a BRCA gene mutation will develop cancer.

THE STAGES OF OVARIAN CANCER

Once you are diagnosed with ovarian cancer, your surgeon determines the stage of the cancer based on how far it has spread from the ovaries. Doctors use a simple staging system for ovarian cancer, numbered 1 to 4.

TUMOR TESTING

Tumor testing analyzes the genes and biomarkers within the tumor. Mutations in genes in the tumor may have been inherited and are present in every cell in the body (including the cancer cells), or the mutations may have arisen just in the cancer cells. It's possible, for example, to test negative for a BRCA mutation in a genetic test that looks at genes that have been inherited, but to test positive for a mutation in a profile of the tumor itself.

Regardless of the origin of the mutations and biomarkers in the tumor, testing the tumor gives information about what may be driving the cancer and therefore what type of treatment you may want to consider at this stage. Targeted therapies are a type of treatment that can act on specific mutations within the cancer cells. One class of targeted therapies that can be considered based on tumor testing is PARP inhibitors, a group of pharmacological inhibitors of the enzyme poly ADP ribose polymerase. Other biomarkers, such as microsatellite instability and tumor mutational burden, can predict response to immunotherapies, which harness the body's own immune system to attack cancer cells.

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 the development of 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.



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

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

- **Stage IA:** The cancer and the tumor are completely inside one ovary.
- **Stage IB:** The cancer is completely inside both ovaries.
- **Stage IC:** The cancer is in one or both ovaries and one or more of the following has occurred:
 - **Stage IC1:** The capsule of the ovary ruptured during surgery.
 - **Stage IC2:** The capsule ruptured before surgery or the cancer is on the outer surface of the ovary.
 - **Stage IC3:** Cancer cells are found in washings.

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.



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. Women who have their surgery done by a gynecologist oncologist have a lower risk of recurrence.

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 IIIA1:** Cancer has spread outside of the pelvis, but only to lymph nodes in the back portion of the abdomen.
 - **Stage IIIA1 (i):** Cancer in the lymph nodes is 10 mm or smaller.
 - **Stage IIIA1 (ii):** Cancer in the lymph nodes is larger than 10 mm.
 - **Stage IIIA2:** Cancer has spread to the tissue lining the abdomen (only visible by microscope) and/or the lymph nodes in the back of the abdomen.
- **Stage IIIB:** Cancer has spread to the tissue lining the abdomen (visible without a microscope) and are 2 cm or smaller. It may have also spread to the lymph nodes in the back of the abdomen.
- **Stage IIIC:** Cancer has spread to the tissue lining the abdomen (visible without a microscope) and are larger than 2 cm. It may have also spread to the lymph nodes in the back of the abdomen or to the outer surface of the liver or spleen.

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

- **Stage IVA:** Cancer cells are found in the fluid around the lungs, but it has not spread outside the abdomen.
- **Stage IVB:** Cancer has spread to the inside of the liver or spleen, distant lymph nodes, or to other organs outside of the abdomen.

CHRISTA, MARYLAND

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

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 most 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.

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?

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?



YOUR HEALTHCARE TEAM

During the course of your treatment for ovarian cancer, you will receive treatment and consultation from many different healthcare professionals in many departments. You will need both good communication skills and a lot of patience. Among those in your “team”:

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

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 approximately 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 foundationforwomenscancer.org or by calling 312-578-1439.

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 CA-125 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?

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. 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.

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 healthcare 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.

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.

MIRNA, NEW YORK

“Being told you have cancer is never something you want to hear, but I had to face that reality when diagnosed with a germ cell tumor almost 2 years ago. I am thankful for the prayers of so many people & give all glory to God for bringing me to the place I needed to be to receive my healing. My faith is now stronger than ever & I am cancer free! As a physician assistant working in oncology, my journey has allowed me to be more empathetic to my patients & for that I am very grateful.”

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.

Questions to Ask When Considering a Clinical Trial

- 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?

RESOURCES



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.
888-OVARIAN (888-682-7426)
ovarian.org

CANCER TRIALS SUPPORT UNIT
888-823-5923
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
877-227-8451
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
877-601-8601
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**
888-NCI-1937 (888-624-1937)
ccr.cancer.gov/clinical-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 wellbeing. 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.

MAL, MASSACHUSETTS

"As a lifelong performer and activist, the only way I know how to effectively process the trauma of my cancer experience is through action. By participating in efforts to raise awareness of ovarian cancer, like being a team captain and running in the annual Run/Walk to Break The Silence on Ovarian Cancer®, by attending local NOCC chapter meetings where we can share our stories and inspire one another, and where, together, we brainstorm new ways to educate ourselves and others to live the best life possible. Being an active participant in a cause larger than myself is the best motivator I know."

JEAN, ILLINOIS

"With little warning and not many symptoms, I was diagnosed with Stage 3C Clear Cell Ovarian Cancer in August 2016. I am an avid runner and triathlete and had just completed a triathlon a couple weeks before my diagnosis. I underwent extensive surgery in early September to remove several tumors, followed by six rounds of chemo. Filled with determination, faith and the belief in positive energy and prayers, and with the support of family and friends, I have been kicking cancer's butt!"

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.

Reiki (ray-kee): 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 (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.

DIFFERENCES BETWEEN COMPLEMENTARY AND ALTERNATIVE MEDICINE

Many people are confused about the differences between “complementary” and “alternative” medicine, often referred to by the acronym CAM. “Complementary medicine” refers to the use of CAM together with conventional medicine, such as using ginger syrup to prevent nausea during chemotherapy. “Alternative medicine” refers to the use of CAM in place of conventional medicine. Many medical experts prefer to use the more contemporary term “integrative medicine” (also called integrated medicine). According to the National Center for Complementary Medicine, integrative medicine refers to a practice that “combines both conventional and CAM treatments for which there is evidence of safety and effectiveness.”



For more information, contact the National Center for Complementary and Alternative Medicine (NCCAM), a federally funded center that supports research on complementary treatments, at 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: nccam.nih.gov/research/camonpubmed.

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.
- Many drug manufacturers have patient assistance programs for women who cannot afford their medication. Check with your physician, or better yet, go to the drug manufacturer directly to discuss these options available.

RESOURCES



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

For more information about talking with family and friends, please access NOCC's brochure entitled "When a Loved One Has Ovarian Cancer," which is available at **OVARIAN.ORG**

If you think you might be interested in a support group, here are some options:

NATIONAL OVARIAN CANCER COALITION

Contact the NOCC to learn if there is a local chapter office in your community, which can provide you with resources and tremendous support, by visiting ovarian.org.

AMERICAN CANCER SOCIETY

The American Cancer Society offers the Cancer Survivors Network and information on local support programs. Call 1-800-ACS-2345 to speak to an information specialist.

CANCERCARE

A national nonprofit that offers 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. All the support groups are led by professional oncology social workers. To learn more, call 1-800-813-4673 or visit cancercare.org.

CANCER HOPE NETWORK

A nonprofit that provides free and confidential one-on-one support to cancer patients and their families. It also offers a social network where you can exchange experiences and share thoughts. Call 1-800-552-4366 or visit cancerhopenetwork.org.

CANCER SUPPORT COMMUNITY (FORMERLY THE WELLNESS COMMUNITY AND GILDA'S CLUB)

This nonprofit offers a variety of free online support groups for people with cancer and their loved ones. Call 1-888-793-9355 or go to cancersupportcommunity.org.

MANAGING YOUR TREATMENT AND COPING WITH SIDE EFFECTS

- **Managing Treatment**
- **What to Expect From Your Treatment**
- **Instant Menopause**
- **Basics of Chemotherapy**
- **Coping with Side Effects**
- **Fatigue and Anemia**
- **Nausea or Vomiting**
- **Hair Loss**
- **Infection**
- **Loss of Appetite and Taste Changes**
- **Mouth Sores or Tender Gums**
- **Constipation and Diarrhea**
- **Nerve and Muscle Problems**
- **Skin Irritation**
- **Pain**
- **Sexual Side Effects**
- **Memory Problems**

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.

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 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

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.

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.

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

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?

DID YOU KNOW?

CHEMOTHERAPY

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 collarbone. 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).

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.

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 your 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.



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 cancer.gov/publications.

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 anti-nausea drugs. If one anti-nausea 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. Therefore, 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 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.

DID YOU KNOW?

CANCER DRUGS

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.

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 have trouble 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.

Use reduced-lactose products. Call your doctor: Check with your doctor before you take antidiarrheal medications or if you have a fever, bloodstools, or severe cramps.

DAWN, NEW JERSEY

"I was diagnosed with Stage IV ovarian cancer in 2010 at the age of 52. My symptoms included indigestion, upper abdominal bloating and fullness, and urinary frequency and urgency, which then were followed by a nagging cough and shortness of breath. I am an active volunteer with the NOCC's New Jersey Chapter and work on many awareness initiatives throughout the state. I started my Run/Walk team, Dawn's Teal Troopers, to help raise awareness for ovarian cancer as well as much needed funds for the NOCC!"

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 sunscreen 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.

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

LYNDA, MARYLAND

"Not only did my life change drastically when I was diagnosed, but my family as a whole. I went from someone that took care of everything to everybody to everybody taking care of me. Ovarian cancer has humbled me in a great way. I was 47 years old when I was diagnosed with stage four ovarian cancer and of the support of my family & God giving me great doctors, I am still here five years later. I just refuse to let ovarian cancer define who I am."

ROSALIND, TEXAS

"Before my first round of chemo I created a survivor journal. It included healing scriptures, cancer 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."

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.



Try to keep your treatment goals in mind. This will help you stay positive on some days when the going gets rough.

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.

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.

SUSAN, NEW YORK

"I had many challenges to overcome in my life but nothing like this challenge of fighting for my life. With all the treatments and procedures there are, as well as the after effects, the mental, physical and emotional changes, you need to prepare yourself to fight the battle. With love and support of my family and friends, I'm able to find a way. I have learned that life is so precious, and I might not be the same person as before but that's ok, it just made me a better version of myself. Peace, love and happiness always."

Protocol: A formalized plan for treatment.

Recurrence: The return of cancer after treatment.

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

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

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

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

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

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.

RESOURCES

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, ovarian.org.

Women's Cancer-Specific Organizations

National Ovarian Cancer Coalition

888-OVARIAN (888-682-7426)

ovarian.org

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

FORCE: Facing Our Risk of Cancer Empowered

866-288-RISK (866-288-7475)

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

312-578-1439

foundationforwomenscancer.org

The 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 Research Fund Alliance

866-399-6262

ocrfa.org

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

General Cancer Information

American Cancer Society
800-ACS-2345 (800-227-2345)
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

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

National Cancer Institute
800-4-CANCER (800-422-6237)
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
888-644-6226
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
877-NCCS-YES (877-622-7937)
canceradvocacy.org

The oldest survivor-led advocacy group in the country. Provides information on cancer support, advocacy, and quality-of-life issues.

Patient/Caregiver Support Organizations

Bright Pink
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.
800-813-HOPE (800-813-4673)
cancercares.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
800-395-LOOK (800-395-5665)
lookgoodfeelbetter.org

Look Good...Feel Better is a free, non-medical, brand-neutral, national public service program to help women offset appearance-related changes from cancer treatment.

Lotsa Helping Hands
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
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 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
planetcancer.org

This is an online community for young adults with cancer.

SHARE
844-ASK-SHARE
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
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 having to travel 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
hhnetwork.org

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

GUIDING WORDS

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

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

Treatment options for women with ovarian cancer are undergoing a revolution. There are hundreds of drugs currently being studied to augment or replace current medications.

You must 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, the NOCC and our local chapters are on your side and always here to help. We're a click away at 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

OUR ANTHEM

There is a ribbon that runs through everything we do. But it's not just a teal symbol for people to wear on their lapels. It is a ribbon forged from hope. From grief. From love. It is a ribbon we use to wrap around those needing comfort as they rebuild. It is a ribbon we use to tie us all together. And it is a ribbon we wave to educate and encourage every woman to be aware. Our enemy is ruthless. And that is why for more than 25 years, the National Ovarian Cancer Coalition has provided a ribbon of courage for women and their families facing the ovarian cancer battle. Together we are strong and we will never back down.

NATIONAL OVARIAN CANCER COALITION

1-888-OVARIAN
WWW.OVARIAN.ORG

Follow Us on Social!



#KNOWOVARIAN

