

THE
Educated Patient®

Ovarian Cancer

RESOURCE GUIDE



Presented by

cure®

A collection of resources that provide information and support for patients and the professionals who treat them



"THERE'S A BRIGHTER TOMORROW
OUT THERE...I THINK
I'M LIVING PROOF OF THAT."

Nancy, Ovarian cancer survivor

Our Way Forward:

Let's Move Forward Together

Our Way Forward is a call to action that encourages women living with ovarian cancer, their loved ones, and healthcare providers to rethink how they talk about ovarian cancer and ways to work together to navigate the physical and emotional challenges that the disease brings.

Explore **ourwayforward.com** to find:

- Videos and stories about life with ovarian cancer by women, care partners, and healthcare providers
- Educational resources to help understand ovarian cancer
- Discussion guides to foster clear and open communication with your oncology care team
- Information about upcoming events for the ovarian cancer community

OUR way
F>>RWARD

FACING OVARIAN CANCER
WITH CONFIDENCE

PATIENT INTRODUCTION

A Life Changed by Ovarian Cancer

Ovarian cancer crept into my life with elusive persistence. At the time of my diagnosis, I had already endured months of pain and anxiety. I had the classic ovarian cancer symptoms: nausea, diarrhea, constipation, frequent urination and unusual fatigue, as well as general abdominal discomfort, bloating and fullness after meals.

My relationships were changing, and my emotions were in a constant state of turmoil. I saw my primary care physician at least once or twice – sometimes as many as three times! – a month. At every visit, I described my symptoms. She gave me everything from anti-nausea drugs (promethazine) to drugs for acid reflux to antibiotics for kidney and urinary tract infections.

I knew something was wrong with me. I had several emergency room visits in late 2005 and one in early 2006, at which CT scans of my abdomen were performed and I was given drugs for acid reflux and nausea. I would leave those visits and every doctor's appointment without answers but with a sense of knowing that something was wrong.

I believe that if I had known about ovarian cancer – the symptoms and the lack of diagnostic testing – I would have been more vigilant. I would have realized that the changes in my body were not “silent” but were there to make me pay attention.

It wasn't until early 2006 that things started to come together. I was given a diagnosis of ovarian cancer; specifically, a rare germ cell tumor called endodermal yolk sac that was rare for someone my age – 39 at the time. Everything happened relatively quickly after that: from diagnosis to surgery to chemo in less than a month. The next four months were tough for me and everyone around me. Going through chemotherapy was particularly difficult, but I made it, and eventually, my cancer went into remission.

Almost 13 years later, it's mind-boggling how far removed I am from my ovarian cancer diagnosis and yet how close I remain. I still can't believe that was me: chemo bound, bald and scared out of my mind. I don't ever want to lose my connection with ovarian cancer. I hate it ... but I love who I have become because of it.



Having a disease like ovarian cancer provided me an opportunity to re-evaluate my life. My world has become broader. I have had the pleasure of meeting ovarian cancer survivors from around the country. I am currently president of the board of directors of a local ovarian cancer awareness and education organization. I have done television interviews, written newspaper and magazine articles, been interviewed for a podcast and spoken at numerous health fairs.

I have a story that needs to be shared so that others will not feel alone in their fight against this insidious disease. I am glad that I can provide some help and support based on my own experience, and I have a responsibility to make the best use of my life to help as many women as I can live strong lives with ovarian cancer. For survivorship to be meaningful to me, it requires a certain level of lasting responsibility.

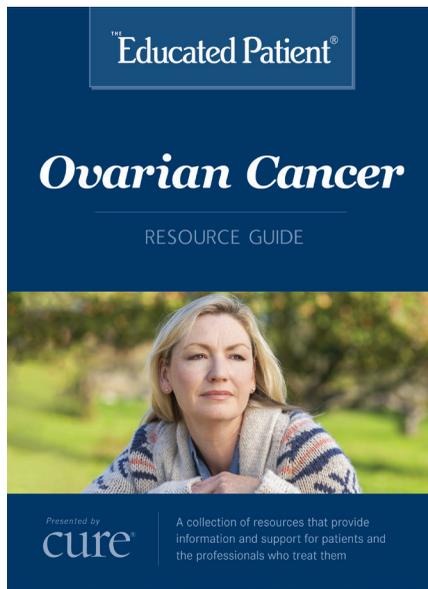
I look to the future and vow to make the best life I can for myself and those I care about; in the process, I hope I touch the lives of others with some of the compassion and love I was given.

The more I do, the more I want to do.

–Kim, ovarian cancer survivor

Table of Contents

- 5** Information About Ovarian Cancer
- 9** Health, Diet and Emotional Support
- 10** Frequently Asked Questions
- 12** Glossary of Important Terms
- 13** Questions to Ask Your Physician
- 16** Patient Education Resources
- 21** Financial Assistance Resources
- 22** Resource Reference Chart



EDITORIAL & PRODUCTION

Senior Vice President
Jeff D. Prescott, PharmD, RPh
 Senior Clinical Project Managers
Ida Delmendo, Danielle Mroz
 Clinical Project Manager
Ted Pigeon
 Senior Manager, Clinical Writing Services
Angelia Szwed
 Copy Chief
Jennifer Potash
 Copy Editors
Maggie Shaw, Rachele Laliberte, Paul Silverman
 Creative Director, Publishing
Ray Pelesko

SALES & MARKETING

Vice President, CURE Media Group
Erik Lohrmann
 Vice President & Executive Producer, MJH Productions
David Lepping
 Director, Patient Education
Marty Murphy
 Senior National Accounts Manager
Brittany Cain
 Marketing Manager
Allison Cooper
 Marketing Associate
Kayla Collins
 Sales and Marketing Coordinator
Mary Osterhout

OPERATIONS & FINANCE

Circulation Director
Jon Severn
 Vice President of Finance
Leah Babitz, CPA
 Controller
Katherine Wyckoff

CORPORATE

Chairman and CEO
Mike Hennessy, Sr
 Vice Chairman
Jack Lepping
 President
Mike Hennessy, Jr
 Chief Operations Officer
George Glatcz
 Chief Financial Officer
Neil Glasser, CPA/CFE
 Executive Creative Director
Jeff Brown
 Executive Vice President, Oncology Professional Relations
Donna Short, MA
 Senior Vice President, Operations
Tom Tolvé
 Senior Vice President, Content
Silas Inman
 Senior Vice President, Information Technology Officer
John Moricone
 Vice President, Corporate Development and Integration
Dave Heckard
 Vice President, Advocacy Development, Oncology & Rare Disease
Sandra Vassos, MPA
 Vice President, Digital Media
Jung Kim
 Vice President, Human Resources and Administration
Shari Lundenberg



2 Clarke Drive, Suite 100
 Cranbury, NJ 08512
 (609) 716-7777

Copyright © 2019 CURE Media Group, LLC.
 All rights reserved.

Information About Ovarian Cancer

Ovarian cancer affects the ovaries, the two small, round organs on either side of the uterus that store reproductive eggs and germ cells and produce the hormones estrogen and progesterone.^{1,2} According to the Centers for Disease Control and Prevention, each year, more than 20,000 women in the United States develop ovarian cancer. Although it accounts for just 2.5 percent of all cancers that occur in women, ovarian cancer accounts for 5 percent of all cancer-related deaths.³ For women in the United States, ovarian cancer is the eighth most common cancer and fifth most common cause of cancer-related death.⁴

When the disease is identified and treated early, as many as 90 percent of those diagnosed can live beyond the five-year milestone.^{2,5} However, only about 15 percent of ovarian cancers are diagnosed in the early stages. The causes of ovarian cancer remain unknown, but more information has emerged about risk factors. All women are at risk of developing ovarian cancer, and older women are more likely to be diagnosed than younger women. According to the CDC, the highest number of ovarian cancers occur in women 60 and older, and approximately 90 percent of women who have ovarian cancer are older than 40.¹

Types of Ovarian Cancer

Of the more than 30 types of ovarian cancer, these three are the most common⁶:

- **Epithelial:** develops from cells that cover the surface of the ovary. It is the most common type, accounting for 85 to 90 percent of all ovarian cancers, and is the most dangerous.
- **Germ:** develops from cells that are destined to form eggs. Most germ cell tumors are noncancerous, although some can be cancerous and dangerous. Approximately 90 percent of patients with ovarian germ cell cancer can be cured and preserve their fertility.
- **Stromal:** develops from cells that release hormones and form tissue connections to the ovaries. Stromal ovarian cancer is rare, with approximately 70 percent of cases presenting in the early stages, in which cancer is limited to one ovary or both of them.

Importantly, patients who are treated for ovarian cancer may be at risk of recurrence.⁷ Approximately 70 percent of patients with ovarian cancer will have recurrence, and

the risk increases with the stage of the cancer at the time of diagnosis.

Risk Factors for Ovarian Cancer

The following factors may increase the risk of ovarian cancer^{1,8-10}:

- Older age (middle age or older).
- Obesity or overweight.
- Family history of ovarian cancer.
- Previous breast, uterine or colorectal cancer.
- Eastern European or Ashkenazi Jewish background.
- Early menses, difficulty with pregnancy or never giving birth.
- Use of fertility treatments.
- Hormone therapy after menopause.
- Endometriosis (tissue from the uterus lining growing in other parts of the body).
- Inherited gene mutations, such as BRCA1 and BRCA2, and those associated with Lynch syndrome.

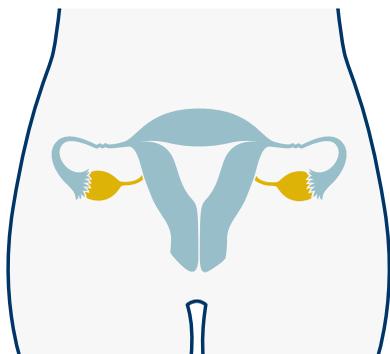
The causes of ovarian cancer are not known. Some research suggests that gene mutations related to ovarian cancer are acquired during a woman's lifetime. Researchers are also studying theories suggesting that the cancer originates in the fallopian tubes or that cancer-causing substances reach the ovaries by first passing through the vagina to the uterus and then the fallopian tubes. Some tests that identify the gene mutations may help predict a patient's prognosis, such as a test to determine changes to the TP53 tumor suppressor gene or the HER2 oncogene. The cause of these gene mutations is unknown and requires further investigation.^{7,8}

Even if you have one or more of these risk factors, you might not develop ovarian cancer. However, it is best to be cautious and speak with your physician and other health care providers about your individual risk.¹ Although there is no guaranteed method to prevent ovarian cancer, certain factors may reduce your risk^{1,7,8,11}:

- **Birth control pills.**
 - Women who have taken birth control pills for at least three to six months may have a lower risk of ovarian cancer. The risk may fall with longer durations of use, and the beneficial effect lasts several years, even after the pill is discontinued.

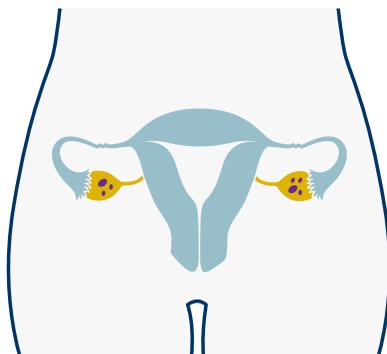
Stages of Ovarian Cancer

BEFORE OVARIAN CANCER



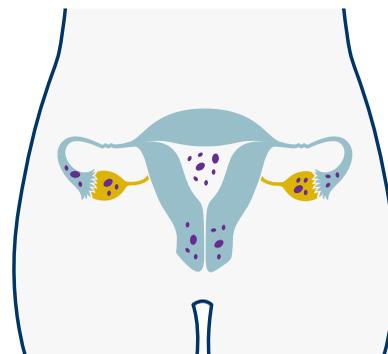
Healthy ovaries

STAGE 1



Cancer is confined to one or both ovaries

STAGE 2



Cancer spreads within the pelvic region

• Pregnancy and giving birth.

- Women who have been pregnant and given birth before age 26 may have a lower risk of ovarian cancer compared with women who have not. With each full-term pregnancy, the risk of ovarian cancer is reduced.

• Gynecologic surgery.

- Tubal ligation (tying the fallopian tubes), hysterectomy (removing the uterus), salpingectomy (removing the fallopian tubes) and oophorectomy (removing the ovaries) may lower the risk of ovarian cancer.

• Breastfeeding.

- Studies have suggested that women who breast-feed for longer than a year may have a lower risk of ovarian cancer.^{1,8}

- Back pain.
- Bloating.
- Changes in appetite (feeling full too quickly or having difficulty eating).
- Frequent urination and/or constipation.

Signs and symptoms of ovarian cancer may be general and difficult to identify. It is estimated that just 15 percent of ovarian cancers are diagnosed in the early stages.¹² Therefore, it is essential to notice if your symptoms are persistent and do not resolve after adjustments to diet, exercise or rest. If you experience any of these signs and symptoms for longer than two weeks, contact your physician. Although something other than ovarian cancer may cause these symptoms, it is best to discuss possible reasons with your physician.¹

Signs and Symptoms

It is important to pay attention to your body and recognize the potential signs and symptoms of ovarian cancer as soon as possible. If you notice unusual or unexplained changes, it is best to contact your physician.¹

Signs and symptoms to watch for include^{1,12}:

- Vaginal bleeding (especially after menopause) or abnormal vaginal discharge.
- Pain or pressure in the area below your stomach and between your hipbones (pelvic/abdominal area).

Diagnosis

For women who do not experience signs or symptoms, it may be difficult to diagnose ovarian cancer. Currently, there is no simple and reliable way to test for ovarian cancer. A normal pelvic exam typically will not identify ovarian cancer unless the physician discovers that the ovary is enlarged. *The Pap test, which samples cells from the cervix, can screen only for cervical cancer and not ovarian cancer.*¹

STAGE 3



Average Stage of Diagnosis: Stage 3C

Cancer spreads to other body parts within the abdomen

STAGE 4



Cancer spreads beyond the abdomen to other body parts

Source: Adapted from The National Ovarian Cancer Coalition.

Although there is no simple, reliable way to screen specifically for ovarian cancer, your physician can offer other tests that may help identify ovarian cancer¹³:

- **Pelvic exam:** Women 18 and older should undergo an annual vaginal exam, and women 35 and older should undergo an annual rectovaginal exam. During a rectovaginal exam, the physician examines the rectum and vagina by feeling for abnormal swelling and tenderness.
- **Transvaginal sonography:** This test involves an ultrasound, in which a small instrument is inserted into the vagina, and may be appropriate for women who have an abnormal pelvic exam or are at high risk of ovarian cancer.
- **Cancer antigen 125 test:** Ovarian cancer cells produce a protein called cancer antigen 125, and women at high risk of ovarian cancer may have elevated blood levels of this substance. Although the CA-125 test is an important test, it is not conclusive. Sometimes ovarian cancers do not elevate CA-125 levels enough to result in a positive test. Additionally, other noncancerous ovarian diseases can elevate CA-125 levels, so a high level does not always point to cancer.

These tests may be useful for women with unexplained signs or symptoms of ovarian cancer or who have had

previous breast, uterine or colorectal cancer or a close relative with ovarian cancer.¹

Staging

Receiving a diagnosis of ovarian cancer also involves staging, which means identifying how far the cancer has spread. Stages are assigned as 1, 2, 3, 4 and each stage may have substages.⁶

- **Stage 1:** Non-invasive cancer. The cancer is in one or both ovaries and has not spread elsewhere in the body.
- **Stage 2:** The cancer is in one or both ovaries and has spread to the fallopian tubes, uterus or other areas in the pelvis.
- **Stage 3:** The cancer is in one or both ovaries and has spread outside the pelvis to the upper abdomen and/or the lymph nodes.
- **Stage 4:** The cancer is in one or both ovaries and has spread to organs outside the abdominal area such as the lungs, spleen, liver, and/or the lymph nodes.

Grading

In addition to staging, patients who receive a diagnosis of ovarian cancer will also receive a grade of the tumor, based on the appearance of the cancer cells under the microscope, compared with healthy tissue. The cancer's grade may help the doctor determine how quickly the

cancer may spread. Grading ranges from GX (unable to be evaluated) to G4 (all or most cells appear abnormal).⁶

Treatment Options

Surgery

Surgical removal of the cancerous growth is the most common method of treatment for ovarian cancer, and most women will undergo surgery during their disease course. The amount of surgery required depends on a woman's overall health and how far the cancer has spread to other parts of the body. It is recommended that a gynecologic oncologist, a specialist who has additional training, perform the surgery.^{14,15}

Surgery may include performing a hysterectomy (removing the uterus), a salpingectomy (removing the fallopian tubes), an oophorectomy (removing the ovaries) or a bilateral salpingo-oophorectomy (removing both ovaries and fallopian tubes). An omentectomy may be done to remove the omentum, the fatty tissue that covers the abdominal organs. Biopsies of lymph nodes and other tissues in the area may also be performed to look for cancer cells. For women who have ovarian cancer in its earliest stage, it may be possible to treat the disease without removing the uterus or both ovaries.¹⁵

Another important goal of surgery is debulking – removing as much of the cancerous tumor as possible. Surgical debulking is important for women whose ovarian cancer has widely spread throughout the abdomen. Optimal debulking occurs when tumors larger than 1 centimeter are eliminated. This may involve removing pieces of the bladder, spleen, gallbladder, liver, stomach or pancreas. Women who have cancerous tumors optimally debulked may have a better prognosis compared with women who have larger tumors remaining after surgery.¹⁵

Chemotherapy

Chemotherapy treats cancer by using chemicals that kill cancer cells or prevent them from growing.¹⁶ Usually, this is a systemic treatment, which means the medication enters the bloodstream and reaches all parts of the body. Chemotherapy agents can be given by mouth, injected into a vein, or delivered through a catheter, a thin tube that can be inserted into the abdominal cavity.^{16,17}

Treatment for ovarian cancer usually combines two or more chemotherapy agents and is administered every three to four weeks. Generally, the treatment takes three to six cycles, which are scheduled doses of medication followed by periods of recovery, but the duration may vary depending on the type of chemotherapy. Ask your physician for more information about the type and duration of chemotherapy you may receive.¹⁷

Targeted Therapy

Targeted therapy works by identifying and attacking cancer cells while trying to minimize the damage on normal, healthy cells. This type of therapy focuses on attacking the inner mechanisms or processes (called pathways) of cancer cells, which are different from those of normal cells. The various types of targeted therapy work on different pathways or cell mechanisms, but generally, the treatments affect a cancer cell's growth, division, repair processes or interactions with other cells.¹⁸

Radiation

Radiation therapy uses high-energy X-rays that shrink tumors by killing cancer cells. The radiation therapy used most often to treat ovarian cancer is a tightly focused stream that targets the cancer directly. Although it is not commonly used for treating ovarian cancer in the United States, radiation therapy can be used to treat areas of the body where the cancer has spread.¹⁹

Hormone Therapy

Hormone therapy involves medication that mimics or, in some cases, blocks hormones to treat cancer. Hormone therapy is not typically used for epithelial ovarian cancer, which is the most common type that affects the outer surface of the ovary; however, it may be used to treat ovarian stromal cancer, a rare type that affects the connective tissues surrounding the ovary.^{6,20}

Clinical Trials

Clinical trials are research studies that investigate new treatments or procedures in a controlled setting. In some cases, clinical trials represent the only opportunity for patients to access promising new therapies. Clinical trials may not be appropriate for everyone; talk to your physician to find out if you may be a candidate for participation.²¹

Health, Diet and Emotional Support

Ovarian cancer may cause a variety of symptoms that affect your daily life. However, making lifestyle modifications can help you maintain your quality of life. This section provides tips and suggestions to help manage your condition, but it is important to talk to your physician before beginning anything new.

Health

When undergoing cancer treatment, it is common to feel fatigue, or extreme tiredness that differs from normal tiredness; for example, you may feel exhausted despite resting. You may experience fatigue even after treatment, which can make it hard to carry out normal daily activities. Although exercise may be difficult initially, studies have shown that it can help reduce fatigue. Patients who follow an exercise program designed for their needs tend to feel better both physically and emotionally. If you are unable to stay active during treatment and have not exercised in some time, it is normal for your strength to decline. It is advisable to start an exercise program slowly, such as by taking short walks.^{22,23}

It is important to care for your health in other ways, too. It may be beneficial to decrease alcohol consumption, attempt to quit smoking and using tobacco products, and reduce stress. Your physician or another health care provider can help you create a plan for important lifestyle changes.²⁴

Patients who are undergoing chemotherapy should also pay attention to their oral health – one-third of patients who are being treated for cancer will experience oral health complications.²⁵ Consider visiting your dentist for a full checkup both before and after treatment. Symptoms such as difficulty swallowing (known as dysphagia), changes in taste, mouth dryness and oral pain should be discussed with your health care provider.

Diet

After cancer treatment, it may be frustrating to try to eat healthy. Treatment may affect your sense of smell and taste, make you nauseous, alter your appetite and cause you to lose or gain weight. It may be helpful to eat small snacks every few hours throughout the day until you can eat larger meals. The American Cancer Society recommends eating a variety of healthy plant-based and protein-rich foods, including 2 ½ cups of produce, such as citrus fruits and dark green or yellow vegetables. Your physician and



health care team may connect you with a dietitian, a nutrition expert who can design a plan that helps you achieve your overall nutrition goals, develop good eating habits and manage treatment side effects.^{26,27}

Emotional Support

Everyone has their own way of coping with life after cancer. When treatment ends, you may experience a wide variety of emotions. Previously, your thoughts may have focused on your treatment and meeting with your health care team. Now, you may feel other issues catching up, or you may have extra time on your hands. You may be experiencing fear over your cancer coming back (called recurrence), and for some individuals, these situations can cause anxiety.²⁴

Almost everyone who has experienced cancer treatment will benefit from support. This can come in the form of friends, family, religious-affiliated groups, online forums and communities, and one-on-one counseling. Choose the form of support that works best for you and is most compatible with your situation and personality.²⁴

Although the cancer journey can be lonely and isolating, you do not have to struggle on your own. Reach out to friends and family who may be willing to help.²⁴ We have compiled some educational and supportive resources that may be useful if you are not sure how to share your concerns or seek assistance. Please see pages 16 through 22 of this guide for more information.

Frequently Asked Questions

What is ovarian cancer?

Ovarian cancer affects one or both ovaries, the small, round organs located on each side of the uterus. An ovary stores reproductive eggs and germ cells and produces the hormones estrogen and progesterone.^{1,2}

How many women have ovarian cancer?

According to the Centers for Disease Control and Prevention, over 20,000 women in the United States develop ovarian cancer each year. Although it accounts for just 2.5 percent of all cancers that occur in women, ovarian cancer results in more deaths than any other cancer related to the female reproductive system. For women in the United States, ovarian cancer is the eighth most common cancer and fifth cause of cancer death behind lung and bronchus, breast, colorectal and pancreatic cancers.⁴

How do I know if I am at risk of ovarian cancer?

The following risk factors may increase the risk of ovarian cancer^{9,10}:

- Older age (middle age or older).
- Obesity or overweight.
- Family history of ovarian cancer.
- Previous breast, uterine or colorectal cancer.
- Eastern European or Ashkenazi Jewish background.
- Early menses, difficulty with pregnancy or never giving birth.
- Use of fertility treatments.
- Hormone therapy after menopause.
- Endometriosis (tissue from the uterus lining growing in other parts of the body).
- Inherited gene mutations, such as BRCA1 and BRCA2, and those associated with Lynch syndrome.

Even if you have one or more of these risk factors, you might not get ovarian cancer. However, it is best to be cautious and speak with your physician and other health care providers about your individual risk.¹

What are the symptoms of ovarian cancer?

Signs and symptoms of ovarian cancer include^{1,12}:

- Vaginal bleeding (especially after menopause) or abnormal vaginal discharge.
- Pain or pressure in the area below the stomach and between the hipbones (pelvic/abdominal area).
- Back pain.

- Bloating.
- Changes in appetite (feeling full too quickly or having difficulty eating).
- Frequent urination and/or constipation.

Signs and symptoms of ovarian cancer may be general and difficult to identify. It is important to notice if your symptoms are persistent and do not resolve after adjustments to diet, exercise or rest. If you experience any of these signs and symptoms for longer than two weeks, contact your physician.¹

What can I do to lower my risk of ovarian cancer?

Although there is no guaranteed way to prevent ovarian cancer, certain factors may reduce your risk^{1,8}:

- Birth control pills.
- Pregnancy and giving birth.
- Gynecologic surgery—tubal ligation (tying the fallopian tubes), hysterectomy (removing the uterus), salpingectomy (removing the fallopian tubes) and oophorectomy (removing the ovaries).
- Breastfeeding.

How is ovarian cancer detected?

For women who do not experience signs or symptoms, it may be difficult to diagnose ovarian cancer. Although there is no simple, reliable way to screen specifically for ovarian cancer, your physician can offer other tests that may help identify ovarian cancer^{1,13}:

- Pelvic exam.
- Transvaginal sonography.
- Cancer antigen 125 blood test (to measure the level of a protein produced by ovarian cancer cells).

These tests may be useful for women with unexplained signs or symptoms of ovarian cancer or those who have had previous breast, uterine or colorectal cancer or a close relative with ovarian cancer.¹

How is ovarian cancer treated?

Potential options for treating ovarian cancer include^{28,29}:

- Surgery.
- Chemotherapy.
- Targeted therapy.
- Radiation.
- Hormone therapy.
- Clinical trials.

cure®

I am more than a patient.
I am an ATHLETE.

Those who have gone through the cancer journey are more than their diagnosis.

They're parents, neighbors, athletes, brothers, teammates – they're #MoreThanAPatient.

At CURE®, we provide insight to everyday people whose lives have been touched by cancer, letting them know that they are not alone. We strive to give readers an identity that goes further than their diagnosis. CURE® makes cancer understandable, and we aim to make life with cancer understandable.

A community of more than just patients. Join us.

Join the conversation on social media using #MoreThanAPatient



cure_magazine



Cure Magazine



CureToday

Glossary of Important Terms

Bilateral salpingo-oophorectomy: surgical removal of both ovaries and both fallopian tubes

Cancer antigen 125: a protein that may be found in high amounts in the blood of patients with certain types of cancer, including ovarian cancer

Chemotherapy: treatment that uses medications to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing; given by mouth, injection or infusion, or topically, depending on type and stage of cancer being treated; used alone or with other treatments such as surgery, radiation therapy or biologic therapy

Clinical trial: a research study that tests how well new medical approaches for screening, prevention, diagnosis or treatment work in people

Debulking: surgical removal of as much of a tumor as possible; may increase the chance that chemotherapy or radiation therapy will kill all the tumor cells and may relieve symptoms

Endometriosis: a condition in which endometrial tissue (the layer of tissue that lines the uterus) grows in abnormal places in the abdomen

Epithelial ovarian cancer: cancer that forms in the tissue covering the ovary; most common type of ovarian cancer

Fallopian tube: one of two slender tubes through which eggs pass from an ovary to the uterus; in the female reproductive tract, there is one ovary and one fallopian tube on each side of the uterus.

Germ cell: a reproductive cell that becomes an egg cell, or ovum, in females and a sperm cell in males

Gynecologic oncologist: a physician who has special training in diagnosing and treating cancers of the female reproductive organs

Gynecologic surgery: surgery related to the female reproductive tract (including the cervix, endometrium, fallopian tubes, ovaries, uterus and vagina)

Hormone: one of many substances that are produced by glands, circulate in the bloodstream and control the actions of certain cells or organs

Hysterectomy: surgery to remove the uterus (partial hysterectomy) and sometimes also the cervix (total hysterectomy)

Oophorectomy: surgery to remove one or both ovaries

Ovary: one of a pair of female glands that produce eggs and the female hormones estrogen and progesterone, which play an important role in breast development, body shape, body hair, menstrual cycle, fertility and pregnancy

Pelvic exam: a physical exam of the vagina, cervix, uterus, fallopian tubes, ovaries and rectum

Radiation therapy: the use of high-energy radiation from X-rays, gamma rays, neutrons, protons and other sources to kill cancer cells and shrink tumors

Salpingectomy: surgical removal of one or both fallopian tubes

Staging: performing tests to learn the extent of the cancer, especially whether the disease has spread from where it first formed to other parts of the body

Stromal cell: a type of cell that makes up certain types of connective tissue

Transvaginal sonography: a procedure to examine the vagina, uterus, fallopian tubes, ovaries and bladder; involves an instrument inserted into the vagina that causes sound waves to bounce off organs inside the pelvis, producing echoes that are sent to a computer that creates a picture called a sonogram

Tubal ligation: an operation to tie the fallopian tubes closed; prevents pregnancy by blocking the passage of eggs from the ovaries to the uterus

*Source: National Cancer Institute Dictionary of Cancer Terms.³⁰
cancer.gov/publications/dictionaries/cancer-terms.*

Questions to Ask Your Health Care Provider

A diagnosis of cancer can be overwhelming. Here are some questions you may want to ask your health care provider, suggested by the American Cancer Society, Cancer Treatment Centers of America and the American Society of Clinical Oncology.³¹⁻³³ Take this list to your appointment; there's space so you can add notes and questions of your own.

What is ovarian cancer?

What causes ovarian cancer?

What are the symptoms of ovarian cancer?

What type of health care provider should I see if I think I might have ovarian cancer?

What type of ovarian cancer do I have?

What are the stage and grade of my ovarian cancer?

What is my expected prognosis?

Has my cancer spread to locations outside my ovaries?

Questions to Ask Your Health Care Provider (Continued)

What treatments do you recommend for me and why?

What is the goal of treatment? Is it to eliminate the cancer or to make me feel better?

How long will treatment take?

What side effects can I expect to feel from my treatment?

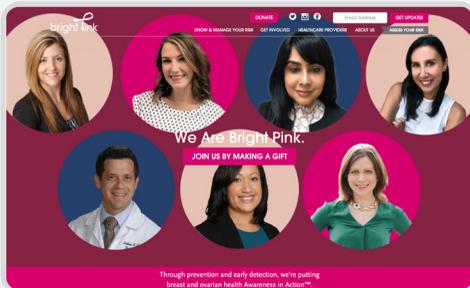
Will my sex life be affected by treatment? If so, for how long?

Will I be able to become pregnant after my treatment?

Could my cancer return after treatment?

How can I preserve my quality of life while I undergo treatment?

What should I know about clinical trials?



ADDRESS:
670 N. Clark St.
Suite 2
Chicago, IL 60654

CONTACT INFO:
Phone: 312-787-4412
Email: through website

Bright Pink

brightpink.org

When Lindsay Avner, the founder of Bright Pink, had a risk-reducing double mastectomy at age 23, she was, at the time, the youngest individual to do so. Bright Pink reaches thousands of lives daily through programs, resources and partnerships. The organization focuses on health and education, not cancer, to educate woman on how to make informed decisions about preventive care.

Resource Checklist

- ✓ Peer-to-peer support programs
- ✓ Risk assessment tools
- ✓ Tips for a healthy lifestyle
- ✓ Materials for health care providers



ADDRESS:
16057 Tampa Palms Blvd. W.
PMB #373
Tampa, FL 33647

CONTACT INFO:
Phone: 866-288-RISK (7475)
Email: info@facingourrisk.org

FORCE: Facing Our Risk of Cancer Empowered

facingourrisk.org

FORCE believes that nobody should face breast and ovarian cancer alone. Coined as the only national nonprofit organization that is dedicated to improving the lives of those who are affected by breast and ovarian cancer, FORCE leads to a wider access of care and awareness for the hereditary community. FORCE has been an outspoken advocacy leader and has designed programs to face the constantly evolving information surrounding hereditary cancer.

Resource checklist

- ✓ Ovarian cancer information
- ✓ Support for families
- ✓ Research and clinical trial information
- ✓ Personalized guidance and support

ADDRESS:
P.O. Box 14066
Huntsville, AL 358 15

CONTACT INFO:
Email: info@liliesofthevalley.org

Lilies of the Valley

liliesofthevalley.org

Lilies of the Valley is an organization available to all patients and survivors who have had any gynecologic cancer. Patients, family members and caregivers can join to spread awareness of the disease and support others who are in similar situations. To fulfill their mission of education and spreading awareness, the organization has support groups that meet monthly and educational “Teal Talks” for anyone interested in the cause.

Resource Checklist

- ✓ Support groups
- ✓ Ovarian cancer information
- ✓ The Lilies of the Valley Garden of Life and Remembrance
- ✓ Teal Talks educational presentations

ADDRESS:
1112 Montana Ave.
Suite 861
Santa Monica, CA 90403

CONTACT INFO:
Phone: 424-272-1749
Email: info@lcfocr.org

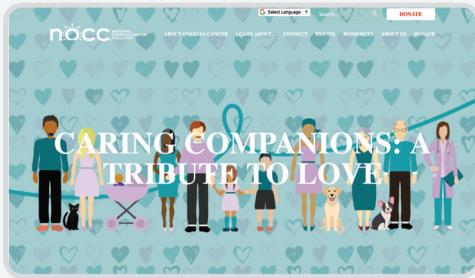
Lynne Cohen Foundation

lynncohenfoundation.org

In 1998, in an effort to fight ovarian and breast cancer through preventive care, education, and community, three sisters founded the Lynne Cohen Foundation in honor of their mother. A dedicated community that focuses on preventive care and early detection, the foundation strives to increase survival rates among women and improve the lives of those affected by cancer.

Resource Checklist

- ✓ Ovarian cancer information
- ✓ Personal stories
- ✓ Fundraising events



ADDRESS:
12221 Merit Drive
Suite 1950
Dallas, TX 75251

CONTACT INFO:
Information line: 888-682-7426
Email: nocc@ovarian.com

National Ovarian Cancer Coalition

ovarian.org

Formed in 1991, the National Ovarian Cancer Coalition advocates for patients with ovarian cancer and their families. The coalition offers national programs and local chapter initiatives to increase education about symptoms, because there is currently no early detection test for ovarian cancer.

Resource Checklist:

- ✓ Ovarian cancer information
- ✓ Awareness and risk assessment information
- ✓ Local chapter events
- ✓ News



ADDRESS:
200 Independence Ave. SW.
Room 712E
Washington, DC 20201

CONTACT INFO:
Health helpline: 800-994-9662

Office on Women's Health

womenshealth.gov

The Office on Women's Health, a faction of the U.S. Department of Health and Human Services, was established in 1991 to ensure that all women and girls achieve the best possible health. Through policy, education and inventive programming, OWH works with federal agencies to improve health for women and girls. The organization also focuses on women's health as a specialized issue for government action.

Resource Checklist

- ✓ Ovarian cancer information
- ✓ Printable fact sheets
- ✓ Health helpline



ADDRESS:
14 Pennsylvania Plaza
Suite 2110
New York, NY 10122

1101 14th St. NW
Suite 850
Washington, DC 20005

CONTACT INFO:
New York City office
Phone: 212-268-1002

Washington, D.C., office
Phone: 866-399-6262

Email: info@ocrahope.org

Ovarian Cancer Research Fund Alliance

ocrfa.org

Since 1998, the Ovarian Cancer Research Fund Alliance has invested over \$85 million in ovarian cancer research and, in 2018, advocated for over \$150 million in government research funding. The organization fights ovarian cancer by financing research for new treatments and much-needed breakthroughs, advocating for patients on Capitol Hill to ensure patient safety and education funding, and supporting survivors through their diagnosis.

Resource Checklist

- ✓ Ovarian cancer information
- ✓ Clinical trials information
- ✓ Community support program
- ✓ Research news
- ✓ Sponsored events



ADDRESS:
79 Main St.
Suite 202
Framingham, MA 01702

CONTACT INFO:
Phone: 508-655-5412
Toll-free: 866-920-6382
Email: susan@ovationsforthecure.org

Ovariations for the Cure of Cancer

ovationsforthecure.org

When Patricia Franchi Flaherty received her second diagnosis of ovarian cancer in 2006, she started Ovariations for the Cure of Ovarian Cancer to fight back against the disease, raise money and increase awareness. With the support of Franchi Flaherty's best friends, the organization began to hold events such as the Stuart Weitzman Fashion Show, which has raised over \$250,000. Overall, Ovariations for the Cure of Ovarian Cancer has raised over \$1.5 million for ovarian cancer research and patient programs.

Resource Checklist

- ✓ Ovarian cancer information
- ✓ Patient programs
- ✓ Fundraising and events



ADDRESS:
165 W. 46th St.
Suite 712
New York, NY 10036

CONTACT INFO:
Phone: 212-719-0364
Toll-free: 844-275-7427
Email: info@sharecancersupport.org

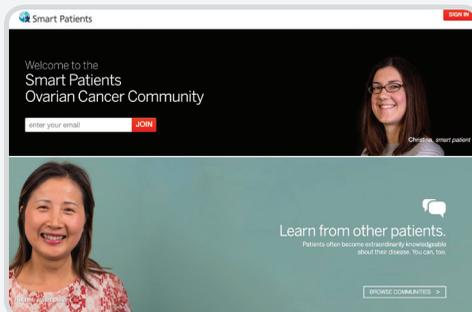
SHARE: Self-Help for Women with Breast or Ovarian Cancer

sharecancersupport.org

Focusing on communities that are medically underserved, SHARE is a nonprofit organization that nationally serves women with ovarian or breast cancer. The organization offers support groups, clinical trial assistance, online communities and many other programs, all free of charge. All services are offered in both English and Spanish.

Resource Checklist

- ✓ Ovarian cancer information
- ✓ National helpline
- ✓ Free webinars and online events
- ✓ Clinical trial matching service
- ✓ Patient support groups



CONTACT INFO:
Email: through website

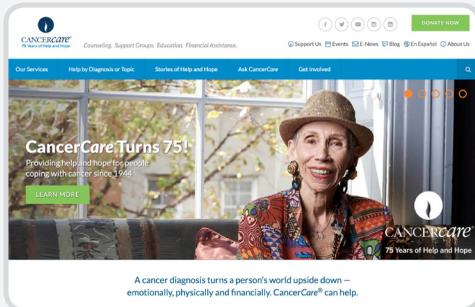
Smart Patients Ovarian Cancer Community

smartpatients.com/communities/ovarian-cancer

Smart Patients is an online community that connects patients and families with others who have different illnesses. The organization believes that patients who become experts in their own conditions are the most underused resource in health care. Through online conversations about personal stories, patients can gain knowledge about their disease and improve the care that they receive. Many treatment options, especially for different types of cancer, are also available through a built-in clinical trial search engine.

Resource Checklist

- ✓ Online support community
- ✓ Recent treatment information
- ✓ Information on clinical trials
- ✓ Personal stories



ADDRESS:
275 Seventh Ave.
22nd Floor
New York, NY 10001

CONTACT INFO:
Phone: 888-813-4637
Email: info@cancercare.org

CancerCare

cancercare.org

Founded in 1944, CancerCare is the leading national organization providing free professional support services and information to help people manage the emotional, practical and financial challenges of cancer. The comprehensive services include counseling and support groups over the phone, online and in person; educational workshops; publications; and financial and copayment assistance. All CancerCare services are provided by oncology social workers and world-leading cancer experts.

Resource Checklist:

- ✓ Counseling with an oncology social worker
- ✓ Patient support groups
- ✓ Publications
- ✓ Financial assistance



ADDRESS:
421 Butler Farm Road
Hampton, VA 23666

CONTACT INFO:
Phone: 800-532-5274
Email: help@patientadvocate.org

Patient Advocate Foundation

patientadvocate.org

The Patient Advocate Foundation recognizes the need for case management services for patients with chronic and debilitating illnesses. Earning many awards in its 20-plus-year history, the organization is dedicated to improving health care access and quality for patients and caregivers. Through policy and programs, the foundation gives a voice to those living with life-threatening diseases.

Resource Checklist:

- ✓ Insurance and financial information
- ✓ Co-pay assistance
- ✓ Free webinars and information sessions

PATIENT EDUCATION RESOURCES

| Website | Address(es) | Contact Information |
|---|--|---|
| Bright Pink brightpink.org | 670 N. Clark St., Suite 2 Chicago, IL 60654 | Phone: 312-787-4412 Email: through website |
| FORCE: Facing Our Risk of Cancer Empowered facingourrisk.org | 16057 Tampa Palms Blvd. W. PMB #373 Tampa, FL 33647 | Phone: 866-288-RISK (7475) Email: info@facingourrisk.org |
| Lilies of the Valley liliesofthevalley.org | P.O. Box 14066 Huntsville, AL 35815 | Email: info@liliesofthevalley.org |
| Lynne Cohen Foundation lynnecohenfoundation.org | 1112 Montana Ave., Suite 861 Santa Monica, CA 90403 | Phone: 424-272-1749 Email: info@lcfocr.org |
| National Ovarian Cancer Coalition ovarian.org | 12221 Merit Drive, Suite 1950 Dallas, TX 75251 | Information line: 888-682-7426 Email: nocc@ovarian.com |
| Office on Women's Health womenshealth.gov | 200 Independence Ave. SW, Room 712E Washington, DC 20201 | Health helpline: 800-994-9662 |
| Ovarian Cancer Research Fund Alliance ocrfa.org | 14 Pennsylvania Plaza, Suite 2110 New York, NY 10122 1101 14th St. NW, Suite 850 Washington, DC 20005 | New York City office Phone: 212-268-1002 Washington, D.C., office Phone: 866-399-6262 Email: info@ocrahope.org |
| Ovarian Problems Discussion List smartpatients.com/communities/ ovarian-cancer | | Email: ovarian-request@listserv.acor.org |
| Ovations for the Cure of Ovarian Cancer ovationsforthecure.org | 79 Main St., Suite 202 Framingham, MA 01702 | Phone: 508-655-5412 Toll-free: 866-920-6382 Email: susan@ovationsforthecure.org |
| Share: Self-Help for Women with Breast or Ovarian Cancer sharecancersupport.org | 165 W. 46th St., Suite 712 New York, NY 10036 | Phone: 212-719-0364 Toll-free: 844-275-7427 Email: info@sharecancersupport.org |

FINANCIAL ASSISTANCE RESOURCES

| Website | Address | Contact Information |
|---|--|--|
| CancerCare cancercare.org | 275 Seventh Ave., 22nd Floor New York, NY 10001 | Phone: 888-813-4637 Email: info@cancercare.org |
| Patient Advocate Foundation patientadvocate.org | 421 Butler Farm Road Hampton, VA 23666 | Phone: 800-532-5274 Email: help@patientadvocate.org |

REFERENCES

1. Inside Knowledge 2016 Ovarian Cancer Factsheet. Centers for Disease Control and Prevention website. https://www.cdc.gov/cancer/ovarian/pdf/ovarian_facts.pdf. Updated September 2016. Accessed January 21, 2019.
2. What is ovarian cancer? National Ovarian Cancer Coalition website. www.ovarian.org/about-ovarian-cancer/what-is-ovarian-cancer. Accessed January 21, 2019.
3. Cancer facts & figures 2018. American Cancer Society website. <https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2018.html>. Accessed January 21, 2019.
4. Ovarian cancer statistics. CDC website. <https://www.cdc.gov/cancer/ovarian/statistics/index.htm>. Updated May 29, 2018. Accessed January 21, 2019.
5. Cancer stat facts: ovarian cancer. National Institutes of Health National Cancer Institute website. <http://seer.cancer.gov/staffacts/html/ovary.html>. Accessed January 23, 2019.
6. Types & stages of ovarian cancer. NOCC website. www.ovarian.org/about-ovarian-cancer/what-is-ovarian-cancer/types-a-stages. Accessed January 21, 2019.
7. What causes ovarian cancer? ACS website. <https://www.cancer.org/cancer/ovarian-cancer/causes-risks-prevention/what-causes.html>. Updated April 11, 2018. Accessed January 21, 2019.
8. Ovarian cancer risk factors. ACS website. <https://www.cancer.org/cancer/ovarian-cancer/causes-risks-prevention/risk-factors.html>. Updated April 11, 2018. Accessed January 21, 2019.
9. Basic information about ovarian cancer. CDC website. https://www.cdc.gov/cancer/ovarian/basic_info. Updated February 13, 2017. Accessed January 30, 2019.
10. Risk factors. Ovarian Cancer Research Alliance website. <https://ocrahope.org/patients/about-ovarian-cancer/risk-factors>. Accessed January 30, 2019.
11. Birth control & cancer: which methods raise, lower risk. ACS website. <https://www.cancer.org/latest-news/birth-control-cancer-which-methods-raise-lower-risk.html>. Published January 21, 2016. Accessed January 30, 2019.
12. What are the signs & symptoms of ovarian cancer? NOCC website. www.ovarian.org/about-ovarian-cancer/what-are-the-signs-a-symptoms. Accessed January 21, 2019.
13. How am I diagnosed with ovarian cancer? NOCC website. www.ovarian.org/about-ovarian-cancer/how-am-i-diagnosed. Accessed January 21, 2019.
14. Ovarian cancer treatment options. NOCC website. www.ovarian.org/about-ovarian-cancer/treatment. Accessed January 21, 2019.
15. Surgery for ovarian cancer. ACS website. <https://www.cancer.org/cancer/ovarian-cancer/treating/surgery.html>. Updated April 11, 2018. Accessed January 21, 2019.
16. Chemotherapy. NOCC website. www.ovarian.org/about-ovarian-cancer/treatment/12-chemotherapy. Accessed January 21, 2019.
17. Chemotherapy for ovarian cancer. ACS website. <https://www.cancer.org/cancer/ovarian-cancer/treating/chemotherapy.html>. Updated April 11, 2018. Accessed January 21, 2019.
18. Targeted therapy for ovarian cancer. ACS website. <https://www.cancer.org/cancer/ovarian-cancer/treating/targeted-therapy.html>. Updated April 11, 2018. Accessed January 21, 2019.
19. Radiation therapy for ovarian cancer. ACS website. <https://www.cancer.org/cancer/ovarian-cancer/treating/radiation-therapy.html>. Updated April 11, 2018. Accessed January 21, 2019.
20. Hormone therapy for ovarian cancer. ACS website. <https://www.cancer.org/cancer/ovarian-cancer/treating/hormone-therapy.html>. Updated April 11, 2018. Accessed January 21, 2019.
21. Treating ovarian cancer. ACS website. <https://www.cancer.org/cancer/ovarian-cancer/treating>. Accessed March 22, 2018.
22. Ovarian cancer resource guide for newly diagnosed women. NOCC website. www.ovarian.org/storage/documents/guides/nocc%202017_newlydiagnosed.pdf. 2017. Accessed January 21, 2019.
23. Managing cancer-related fatigue. ACS website. <https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fatigue/managing-cancer-related-fatigue.html>. Updated October 22, 2018. Accessed January 23, 2019.
24. Life after cancer. ACS website. <https://www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/life-after-cancer.html>. Updated February 12, 2016. Accessed January 21, 2019.
25. Understanding the oral complications from cancer treatment. National Comprehensive Cancer Network website. https://www.nccn.org/patients/resources/life_with_cancer/treatment/oral_complications.aspx. Accessed January 23, 2019.
26. Nutrition for the person with cancer during treatment. ACS website. <https://www.cancer.org/treatment/survivorship-during-and-after-treatment/staying-active/nutrition/nutrition-during-treatment.html>. Accessed January 23, 2019.
27. How to cope with common eating problems. ACS website. <https://www.cancer.org/treatment/survivorship-during-and-after-treatment/staying-active/nutrition/nutrition-during-treatment/common-problems.html>. Updated July 15, 2015. Accessed January 23, 2019.
28. How is ovarian cancer treated? CDC website. https://www.cdc.gov/cancer/ovarian/basic_info/treatment.htm. Updated February 13, 2017. Accessed January 21, 2019.
29. Ovarian cancer treatment options. NOCC website. www.ovarian.org/about-ovarian-cancer/treatment. Accessed January 21, 2019.
30. NCI Dictionary of Cancer Terms. NCI website. <https://www.cancer.gov/publications/dictionaries/cancer-terms>. Updated 2018. Accessed January 21, 2019.
31. What should you ask your doctor about ovarian cancer? ACS website. <https://www.cancer.org/cancer/ovarian-cancer/detection-diagnosis-staging/talking-with-doctor.html>. Updated April 11, 2018. Accessed January 21, 2019.
32. Top questions about ovarian cancer. Cancer Treatment Centers of America website. <https://www.cancercenter.com/ovarian-cancer/questions>. Updated June 28, 2018. Accessed January 21, 2019.
33. Ovarian, fallopian tube, and peritoneal cancer: questions to ask the doctor. American Society of Clinical Oncology website. <https://www.cancer.net/cancer-types/ovarian-fallopian-tube-and-peritoneal-cancer/questions-ask-health-care-team>. Accessed January 21, 2019.

