



Dear Friend:

As shocking as it can be to receive a diagnosis of ovarian or endometrial cancer, we at the Ovarian and Gynecologic Cancer Coalition/Rhonda's Club want you to know that **NO ONE FIGHTS ALONE.**

The Ovarian and Gynecologic Cancer Coalition (OGCC)/Rhonda's Club pursues a mission to battle gynecologic cancers by raising public awareness of symptoms, educating survivors and medical professionals, and supporting research to improve quality of life, and find the cures. In the twenty years since our founding, access to quality medical information has improved. What has not changed, however, is the need for compassion for those in treatment. At OGCC/Rhonda's Club we understand there are women who could use extra helpings of care and support as they face treatment for gynecologic cancers.

With this in mind, OGCC/Rhonda's Club offers you as a gift this patient care bag with a few comfort gifts and information to help you better understand aspects of your illness and treatments and find national and local resources to help navigate your way back to health.

We hope this patient care bag, which was inspired and initiated by our late Board member, Binnie Fry, will ease your journey.

OGCC/Rhonda's Club also offers informal outreach from other survivors of ovarian cancer. If you would like to talk with someone who has come through the cancer experience, feel free to leave a message at 703-346-3893 or ogccmail@gmail.com and someone will contact you. For more information about OGCC, visit our website at www.rhondasclub.org. Please send feedback about this patient care bag to ogccmail@gmail.com so we can improve it.

With warmest wishes,

JoAnn Symons, Chair
and Your Friends at OGCC/Rhonda's Club



Contact Information

Website: www.rhondasclub.org

Email Address: ogccmail@gmail.com

Mailing Address: P.O. Box 12504
Arlington, VA 22219

Phone: 703-346-3893

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Uterine/Endometrial Cancer Overview

Cancer occurs when cells in an area of the body grow abnormally. The endometrium is the lining layer of the uterine cavity where most uterine cancers begin because of cancerous changes in the lining. In the most common type of uterine cancer, endometrial cancer, cells in the endometrial lining grow out of control, may invade the muscle of the uterus and sometimes spread outside of the uterus (ovaries, lymph nodes, abdomen).

Uterine sarcomas are a type of uterine cancer in which malignant cells form in the muscle of the uterus (leiomyosarcoma) or in the network of support cells in the uterine lining (stromal sarcomas and carcinosarcomas). Only about 5% of uterine cancers are uterine sarcomas, but they tend to have more aggressive clinical behavior and can spread quickly. See the enclosed booklet “Understanding Endometrial Cancer: A Woman’s Guide” for more information.

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Ovarian Cancer Overview

Ovarian cancer is a growth of abnormal malignant cells that begins in the ovaries (women’s reproductive glands that produce ova). Cancer that spreads to the ovaries but originates at another site is not considered ovarian cancer. Ovarian tumors can be benign (noncancerous) or malignant (cancerous). Although abnormal, cells of benign tumors do not metastasize (spread to other parts of the body). Malignant cancer cells in the ovaries can metastasize in two ways:

- directly to other organs in the pelvis and abdomen (the more common way)
- through the bloodstream or lymph nodes to other parts of the body.

While the causes of ovarian cancer are unknown, some theories exist:

- Genetic errors may occur because of damage from the normal monthly release of an egg.
- Increased hormone levels before and during ovulation may stimulate the growth of abnormal cells.

Types of Ovarian Cancer

Different types of ovarian cancer are classified according to the type of cell from which they start.

Epithelial tumors – About 90 percent of ovarian cancers develop in the epithelium, the thin layer of tissue that covers the ovaries. This form of ovarian cancer generally occurs in postmenopausal women.

Germ cell carcinoma tumors – Making up about five percent of ovarian cancer cases, this type begins in the cells that form eggs. While germ cell carcinoma can occur in women of any age, it tends to be found most often in women in their early 20s. Six main kinds of germ cell carcinoma exist, but the three most common types are: teratomas, dysgerminomas, and endodermal sinus tumors. Many tumors that arise in the germ cells are benign.

Stromal carcinoma tumors – Ovarian stromal carcinoma accounts for about five percent of ovarian cancer cases. It develops in the connective tissue cells that hold the ovary together and those that produce

the female hormones estrogen and progesterone. The two most common types are granulosa cell tumors and sertoli-leydig cell tumors. Unlike with epithelial ovarian carcinoma, 70 percent of stromal carcinoma cases are diagnosed in Stage I.

Small cell carcinoma of the ovary – Small cell carcinoma of the ovary (SCCO) is a rare, highly malignant tumor that affects mainly young women, with a median age at diagnosis of 24 years old. The subtypes of SCCO include pulmonary, neuro-endocrine and hypercalcemic. SCCO accounts for 0.1 percent of ovarian cancer cases. Approximately two-thirds of patients with SCCO have hypercalcemia. The symptoms are the same as other types of ovarian cancer.

Stages of Ovarian Cancer

The stages of ovarian cancer are determined by how far the cancer has spread. The stage of ovarian cancer at diagnosis is the most important indicator of prognosis.

Stage I – Cancer is limited to one or both ovaries.

IA – Cancer is limited to one ovary and the tumor is confined to the inside of the ovary. No ascites containing malignant cells is present, and the surface of the tumor has not ruptured.

IB – Cancer is limited to both ovaries without any tumors on the ovaries' outer surfaces. No ascites containing malignant cells is present, and the surface of the tumor has not ruptured.

IC – The tumor is classified as either Stage IA or IB and one or more of the following conditions exist:

- a tumor on the outer surface of one or both ovaries;
- at least one ruptured tumor;
- ascites or abdominal (peritoneal washings) containing malignant cells.

Stage II – The tumor involves one or both ovaries and extends to other pelvic structures.

IIA – The cancer has extended to and/or involves the uterus and/or the fallopian tubes.

IIB – The cancer has extended to the bladder or rectum.

IIC – The tumor is classified as either Stage IIA or IIB and one or more of the following conditions exist:

- a tumor on the outer surface of one or both ovaries;
- at least one ruptured tumor;
- ascites containing malignant cells or abdominal (peritoneal washings) containing malignant cells.

Stage III – The tumor involves one or both ovaries, and one or both of the following exist:

- the cancer has spread beyond the pelvis to the lining of the abdomen;
- the cancer has spread to the lymph nodes.
- the tumor is limited to the true pelvis but with histologically-proven malignant extension to the small bowel or omentum (peritoneum fold).

IIIA – The tumor is in one or both of the ovaries. While surgeons cannot see cancer in the abdomen, and the cancer has not spread to the lymph nodes, biopsies checked under a microscope reveal tiny deposits of cancer in the abdominal (peritoneal) surfaces.

IIIB – The tumor is in one or both ovaries, and deposits of cancer are present in the abdomen that are large enough for the surgeon to see but do not exceed two cm in diameter. The cancer has not spread to the lymph nodes.

IIIC – The tumor is visible in one or both ovaries, and one or both of the following conditions exists:
the cancer has spread to lymph nodes;
the deposits of cancer exceed two cm in diameter and are found in the abdomen.

Stage IV- Growth of the cancer involves one or both ovaries and distant metastases to the liver or lungs have occurred. Finding ovarian cancer cells in the excess fluid accumulated around the lungs (pleural fluid) also shows evidence of stage IV.

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Risk Factors

While most women with ovarian cancer do not have any known risk factors, some do exist. If a woman has one or more risk factors, she will not necessarily develop ovarian cancer; however, her risk may be higher than the average woman's.

Genetics: *BRCA1* and *BRCA2*

About 10 to 15 percent of women diagnosed with ovarian cancer have a hereditary tendency to develop the disease. The most significant risk factor for ovarian cancer is an inherited genetic mutation in one of two genes: breast cancer gene 1 (*BRCA1*) or breast cancer gene 2 (*BRCA2*). These genes are responsible for about 5 to 10 percent of all ovarian cancers.

Eastern European women and women of Ashkenazi Jewish descent are at a higher risk of carrying *BRCA1* and *BRCA2* mutations.

Since these genes are linked to both breast and ovarian cancer, women who have had breast cancer have an increased risk of ovarian cancer.

Genetics: HNPCC/Lynch Syndrome

Another known genetic link to ovarian cancer is an inherited syndrome called hereditary nonpolyposis colorectal cancer (HNPCC or Lynch Syndrome). While HNPCC poses the greatest risk of colorectal cancer, women with HNPCC have about a 12 percent lifetime risk of developing ovarian and a 40-60 percent chance of developing uterine cancer.

Family History

Family history of any of the following cancers may indicate an increased risk: Breast cancer, Ovarian cancer, Colon cancer, Uterine cancer.

Women who have one first-degree relative with ovarian cancer but no known genetic mutation still have an increased risk of developing ovarian cancer. The lifetime risk of a woman who has a first degree relative with ovarian cancer is five percent (the average woman's lifetime risk is 1.4 percent).

While it accounts for only a limited number of cases, heredity is a strong risk factor for ovarian cancer. Maternal and family history should be considered, however, many women without a family history may still have a gene mutation associated with risk for ovarian cancer. All women diagnosed with ovarian cancer, primary peritoneal or fallopian tube cancer should be referred for genetic counseling and consideration of genetic testing.

Increasing Age

All women are at risk of developing ovarian cancer regardless of age; however, ovarian cancer rates are highest in women aged 55-64 years. The median age at which women are diagnosed is 63, meaning that half of women are younger than 63 when diagnosed with ovarian cancer and half are older.

Reproductive History and Infertility

Research suggests a relationship between the number of menstrual cycles in a woman's lifetime and her risk of developing ovarian cancer. A woman is at an increased risk if she:

- started menstruating at an early age (before 12),
- has not given birth to any children,
- had her first child after 30,
- experienced menopause after 50,
- has never taken oral contraceptives.

Infertility, regardless of whether or not a woman uses fertility drugs, also increases the risk of ovarian cancer.

Hormone Replacement Therapy

Doctors may prescribe hormone replacement therapy to alleviate symptoms associated with menopause (hot flashes, night sweats, sleeplessness, vaginal dryness) that occur as the body adjusts to decreased levels of estrogen. Hormone replacement therapy usually involves treatment with either estrogen alone (for women who have had a hysterectomy) or a combination of estrogen with progesterone or progestin (for women who have not had a hysterectomy).

Women who use menopausal hormone therapy are at an increased risk for ovarian cancer. Recent studies indicate that using a combination of estrogen and progestin for five or more years significantly increases the risk of ovarian cancer in women who have not had a hysterectomy. Ten or more years of estrogen use increases the risk of ovarian cancer in women who have had a hysterectomy.

Obesity

Various studies have found a link between obesity and ovarian cancer. A 2009 study found that obesity was associated with an almost 80 percent higher risk of ovarian cancer in women 50 to 71 who had not taken hormones after menopause.

Reducing Risk

Women can reduce the risk of developing ovarian cancer in many ways; however, ***there is no prevention method for the disease***. All women are at risk because ovarian cancer does not strike only one ethnic or age group. A health care professional can help a woman identify ways to reduce her risk as well as decide if consultation with a genetic counselor is appropriate.

Oral Contraceptive Use

The use of oral contraceptives (birth control pills) decreases the risk of developing ovarian cancer, especially when used for several years. Women who use oral contraceptives for five or more years have about a 50 percent lower risk of developing ovarian cancer than women who have never used oral contraceptives.

Pregnancy and Breastfeeding

Pregnancy and breastfeeding are linked with a reduced risk of ovarian cancer, likely because women ovulate less frequently when pregnant or breastfeeding.

Removal of the Ovaries

Women can greatly reduce their risk of ovarian cancer by removing their ovaries and fallopian tubes, a procedure known as prophylactic bilateral salpingo oophorectomy. One study suggests that women with *BRCA1* mutations gain the most benefit by removing their ovaries before age 35.

There are risks associated with removing the ovaries and fallopian tubes; women should speak to their doctors about whether this procedure is appropriate for them.

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Treatment

Navigating and understanding treatment options are critical for an ovarian cancer patient's survival. All treatment decisions should be made by a patient in consultation with her medical professional.

The standard treatment for ovarian cancer consists of debulking surgery followed by six rounds of chemotherapy. One recent study found that just 37 percent of women receive this standard treatment, despite evidence showing that it is the most effective.

Surgery

During surgery, doctors attempt to remove all visible tumors (tumor debulking). Women whose surgery was performed by a gynecologic oncologist have better outcomes than patients whose surgeons were not oncologists, including improved survival and longer disease-free intervals.

Chemotherapy

Patients undergo chemotherapy in an effort to kill any cancer cells that remain in the body after surgery.

Intraperitoneal Chemotherapy

This therapy places the medicine directly into the peritoneal area through a surgically implanted port and catheter. While intraperitoneal (IP) therapy has been in use since the 1950s, new advances have combined it with intravenous (IV) therapy, using chemotherapy agents that work best for treating ovarian cancer. The National Cancer Institute recommends that, for select ovarian cancer patients, chemotherapy be given by both IV and IP. This combination has been found to increase survival for women with advanced stage ovarian cancer.

Neoadjuvant Chemotherapy

Some patients may receive chemotherapy before having surgery to remove their tumors. This is known as neoadjuvant chemotherapy.

Other Drugs

Other drugs, including angiogenesis inhibitors and targeted therapies, may be recommended either in conjunction with chemotherapy or as single agents. These drugs may have very different side-effects than chemotherapies and may be useful only for specific populations.

Radiation Therapy or Radiotherapeutic Procedures

These procedures may be used to kill cancer cells that remain in the pelvic area.

Side Effects

The goal of chemotherapy is to eliminate rapidly growing cancerous cells; however, some drugs are unable to differentiate between cancerous cells and other frequently dividing cells. As a result, the drugs can kill cells found in the bone marrow, digestive tract, hair follicles, and reproductive organs. Every woman experiences different side effects depending on the type and dosage of her chemotherapy.

treatments. Women undergoing treatment should talk to their medical professionals about the best way to address their side effects.

Hair Loss

Some chemotherapy drugs damage hair follicles, causing loss of body hair. Hair loss typically begins two to three weeks after the first treatment and may affect not only the hair on a woman's head but also her eyebrows, eyelashes, facial hair, pubic hair, underarm hair and leg hair. While hair loss can be extensive, it is almost always temporary. Women's hair usually grows back once treatment ends. Some women cope with hair loss by cutting their hair or shopping for a wig before losing any hair.

Nausea and Vomiting

Since nausea is such a common side effect of chemotherapy, doctors will often prescribe antiemetics to minimize suffering. Antiemetics work by blocking signals between the brain and stomach to stop vomiting. These side effects must be managed during chemotherapy treatments because uncontrolled vomiting and nausea can interfere with the patient's ability to receive treatments. Complementary therapies, such as ginger, exist and are proven to reduce nausea.

Fatigue

Cancer patients experience fatigue for many reasons—not all of which are known. Both cancer and cancer treatments can cause fatigue. Fatigue is a common side effect following radiation and chemotherapy. Medication used to treat pain, depression, vomiting, seizures, and other side effects may cause fatigue. Fatigue usually lessens after treatment ceases, but sometimes people never regain their full energy.

Diarrhea and Constipation

Diarrhea is a common side effect of chemotherapy that usually occurs in the days immediately following a chemotherapy treatment. Patients with diarrhea need to remember that they can become dehydrated quickly and should be sure to hydrate themselves. Some patients may experience constipation due to chemotherapy, the after effects of surgery, or anti-nausea drugs. Doctors often tell patients who experience constipation to take a mild laxative or stool softener. Patients experiencing constipation should drink plenty of liquids.

Nerve Problems

Certain chemotherapy drugs can cause peripheral neuropathy, an increase in numbness caused by damage to the nerves that transmit signals between extremities and the central nervous system. This damage to the nerves often causes a tingling sensation or loss of control in the hands or feet. Acupuncture or massage and physical therapy may lessen these side effects, which are usually temporary and improve or resolve when chemotherapy treatment stops.

Mouth Issues

Chemotherapy can kill the cells lining the mouth, throat, and gastrointestinal tract, causing mouth sores. Mouth issues are particularly bad for patients who receive high doses of chemotherapy, have poor oral and dental health prior to treatment, or have kidney or concomitant disease. Smoking, using tobacco, and consuming harsh foods or alcohol increase the severity of these side effects. Some chemotherapy drugs create taste changes in patients. Food may taste salty or bitter but usually tastes normal again once treatment is over. Non-alcoholic mouthwash and other products can decrease dryness of the mouth.

Sexuality and Intimacy Issues

Interest in sexual intimacy often decreases for chemotherapy patients for many reasons, including additional stress and the side effects of treatment. Patients need to maintain a positive self image during this time and sustain open communication with their partners. When a patient is ready to engage in sexual activity, she should consider taking the following actions:

- Make time for rest before and after sexual activity to preserve energy.
- Use water-soluble lubricants as her vagina may be drier than usual due to hormonal changes.
- Experiment to find comfortable positions and avoid those that will tire her quickly.

“Chemobrain”

Many women experience forgetfulness and have trouble with concentration after receiving chemotherapy. This absentmindedness is often temporary; however, about 15 percent of chemo patients experience permanent problems. Since the cause is unknown, no treatment exists for this side effect. Women who have experienced this side effect offer several suggestions for dealing with it:

- Minimize distractions while performing important tasks.
- Keep a daily organizer/journal to keep track of appointments.
- Use the calendar on your computer and voicemail messages to remind yourself of meetings.

After Treatment

Follow-up Plan

After the initial treatment is over, a woman should have follow-up treatments with her doctor. During follow-ups, doctors do thorough physical exams and may also monitor a patient's blood for an elevated CA-125 level. Some patients have a sensitive CA-125 that will rise before their CT scan shows evidence of recurrent disease; a recent study suggests that it may be more useful to wait until a woman experiences symptoms of ovarian cancer before starting treatment. Others will have evidence of the disease before their CA-125 rises. Doctors often use a combination of tests to monitor a patient because recurrent ovarian cancer has a wide spectrum of behavior making it difficult to monitor. In addition to physical exams and a CA-125 test, doctors may request CT and/or PET scans to look for tumor growth.

A patient should discuss a follow-up plan and survivorship plan with her physician, clearly outlining a plan of action post treatment. A survivorship plan that addresses long-term issues is critical for a woman to have and discuss with her regular internist and other health care professionals outside of her cancer treatment. CA-125 plus HE4 have been approved by the Food and Drug Administration (FDA) for monitoring.

Recurrence

When cancer returns after a period of remission, it is considered a recurrence. A cancer recurrence happens because some cancer cells were left behind and eventually grow and become apparent. The cancer may come back to the same place as the original tumor or to another place in the body. Around 70 percent of patients diagnosed with ovarian cancer will have a recurrence.

One of the factors in determining a patient's risk of recurrence is the stage of the cancer at diagnosis:

- Patients diagnosed in stage I have a 10 percent chance of recurrence.
- Patients diagnosed in stage II have a 30 percent chance of recurrence.
- Patients diagnosed in stage III have a 70 to 90 percent chance of recurrence.
- Patients diagnosed in stage IV have a 90 to 95 percent chance of recurrence.

Recurrent ovarian cancer is treatable but rarely curable. Women with recurrent ovarian cancer may have to undergo another surgery. Because many women with recurrent ovarian cancer receive chemotherapy for a prolonged period of time, sometimes continuously, the toxicities of therapy are a major factor in treatment decisions.

The effectiveness and type of treatment for recurrent ovarian cancer depends on what kind of chemotherapy the patient received in the past, the side effects associated with previous treatments, the length of time since finishing the previous treatment, and the extent of the recurrent cancer. Chemotherapy is used to stop the progression of cancer and prolong the patient's survival. Sometimes, surgery is used to relieve symptoms, such as a blocked bowel caused by the recurrence. In select patients, surgery for debulking of cancer is also an option.

A woman, in consultation with her doctor, should set realistic goals for what to expect from treatment. This may mean weighing the possible positive outcomes of a new treatment against the possible negative ones. At some point, a woman may decide that continuing treatment is unlikely to improve her health or survival. A woman must be certain that she is comfortable with her decision whatever it is.

Clinical Trials

Researchers carry out ovarian cancer clinical trials to find ways of improving medical care and treatment for women with this disease. A woman is eligible to participate in a clinical trial at any point in her experience with ovarian cancer: before, during or after treatment. Many women think of clinical trials as an option only after other treatments have failed. Clinical trials exist for women in this situation, but many equally important trials are available for women earlier in their fight against ovarian cancer.

Resources on Clinical Trials

Women can explore clinical trial options by visiting the Ovarian Cancer Research Fund Alliance Clinical Trials Matching Service at: <http://www.emergingmed.com/networks/ocna/> or by calling (800) 535-1682.

The Ovarian Cancer Research Fund Alliance has a helpful discussion of commonly asked questions, concerns and misperceptions about clinical trials at: <http://www.ovariancancer.org/resources/clinical-trials/common-questions-concerns-and-misperceptions/>

The National Cancer Institute has a comprehensive section on their web site called "Learning About Clinical Trials." You can access it at: <http://www.cancer.gov/about-cancer/treatment/clinical-trials>

The American Cancer Society has information on "Clinical Trials: What You Need to Know at: <http://www.cancer.org/acs/groups/cid/documents/webcontent/003006-pdf.pdf>

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Gynecologic Cancer Support Groups in the Washington, D.C. Region

In general, these support groups are free to cancer survivors, their families, and friends. We suggest calling ahead to confirm dates and locations.

Throughout the Region:

Look Good Feel Better

Look Good Feel Better is a national program of group workshops that teach beauty techniques to female cancer patients to help them combat the appearance-related side effects of cancer treatment. Local sessions are offered at Medstar Washington Hospital Center, Howard University Hospital, Sibley Memorial Hospital, Georgetown Lombardi Comprehensive Cancer Center, and Life with Cancer Family Center. In Baltimore, organizations participating in the program include: Saint Agnes Hospital, Greater Baltimore Medical Center, U of MD St. Joseph Medical Center, Hopewell Cancer Support, Sinai Hospital, American Cancer Society Baltimore Hope Lodge, and Upper Chesapeake Health System Inc.

To find locations and schedules for programs, check the website at: <http://lookgoodfeelbetter.org> or call 1-800-395-5665.

In Washington, DC:

Gynecologic Oncology Support Group

Where: Sibley Memorial Hospital, Renaissance Building, Sullivan Center for Breast Imaging Conference Room

When: 2nd Tuesday of each month

Contact: Meagan Paultk, MSW, 202-537-4107 or mpaultk2@jhmi.edu

Smith Center for Healing and the Arts

Where: 1632 U Street, NW

Washington, DC 20009

When: General cancer support group every Monday at 6:00-7:30 p.m. Young adults cancer support group one Sunday every month at 5:00 p.m. Call for schedules and times or view the calendar on the website.

Contact: (202) 483-8600, www.smithcenter.org

In Maryland:

Gynecologic Cancer Support Group

Holy Cross Hospital Cancer Institute

Where: **Holy Cross Hospital Professional and Community Education Center**

1500 Forest Glen Road

Silver Spring, MD 20910

When: 3rd Wednesday of every month, 6:30-8:00 pm

Contact: 301-557-1850

Comments: Phone registration preferred, but not required.

HopeWell Ovarian Cancer Support Group

Where: HopeWell Cancer Support

10628 Falls Road

Lutherville, MD 21093

When: 2nd and 4th Thursdays every month, 7:30 - 9:00 pm

Contact: 410-832-2719, www.hopewellcancersupport.org

Ovarian and Gynecologic Cancer Support Group

Where: **Hope Connections for Cancer Support**

Beaumont House at FASEB

9650 Rockville Pike

Bethesda, MD 20814

When: 2nd & 4th Monday of every month, 12:30-2:30 p.m.

Contact: 301-634-7500, www.hopeconnectionsforcancer.org

Where: **Hope Connections for Cancer Support**

8401 Corporate Drive

Landover, MD

Contact: 301-634-7500, www.hopeconnectionsforcancer.org

Comments: Opening in October, 2016. Check website for program guide.

Continued on next page....

In Virginia:

Gynecologic Cancers Support Group

Where: Life With Cancer

8411 Pennell St.

Fairfax, VA 22031

When: 4th Wednesday of every month, 5:30-7:00 p.m.

ALSO AT....

Where: (second location): Fair Oaks Cancer Center
Life with Cancer Suite

When: 3rd Tuesday of every month, 6:30-8:00 p.m.

Contact: 703-206-5433, www.lifewithcancer.org

Comments: Sponsored by Inova Fairfax Hospital

Online:

Online support groups are available for those who prefer anonymity or can't meet outside their home.

Association of Cancer Online Resources (ACOR)

Contact: www.acor.org

Comments: Find an ovarian problems discussion list by clicking on "browse the full list of communities" and choosing "ovarian cancer."

Ovarian Cancer Research Fund Alliance Support Community

Contact: www.inspire.com/groups/ovarian-cancer

Comments: Connects patients, families, friends and caregivers for support and inspiration. Sponsored by the Ovarian Cancer Research Fund Alliance in partnership with Inspire.

CancerCare

Contact: www.cancercare.org, 1-800-813-4673

CancerCare is a national nonprofit organization that provides free online and telephone support groups led by professional oncology social workers for anyone affected by cancer.

Sharsheret

Contact: www.sharsheret.org, 1-866-474-2774

Comments: specialized support for Jewish women living with ovarian cancer. Phone and online counseling with peer network of survivors and genetic counselors. Free caregiver information packets and resource booklets available. Sign up for teleconferences and seminars online or by telephone.



Frequently Asked Questions

Ovarian Cancer Myths

Does promoting ovarian cancer information increase anxiety among women?

A scientific study in Britain dispelled this idea; promoting cancer information really reassures the public. (British Medical Journal 1999) It is important to empower women with the knowledge to take charge of their health and be good advocates for themselves.

Is it true that a woman who has had her ovaries removed cannot get ovarian cancer?

Technically, women who have their ovaries removed cannot get ovarian cancer. There is a rare type of cancer called primary peritoneal carcinoma – a close relative to ovarian cancer that can develop without the ovaries.

Does ovarian cancer have symptoms in its early stages?

While the symptoms for ovarian cancer tend to be nonspecific and can mimic nongynecologic conditions, a large national study shows that an overwhelming majority of women diagnosed with ovarian cancer did have symptoms, sometimes even in the early stages. The most common symptoms reported include: abdominal bloating or discomfort; increased abdominal size or clothes that fit tighter around your waist; increased or urgent need to urinate and pelvic pain. Additional signs and symptoms are: Persistent gas, indigestion or nausea; unexplained changes in bowel habits; unexplained weight loss or gain; loss of appetite; feeling full quickly during or after a meal and pain during sexual intercourse; a persistent lack of energy, low back pain and shortness of breath.

Source: A. Goff, M.D., Lynn Mandel, Ph.D., Howard G. Muntz, M.D., Cindy H. Melancon, R.N., M.N. 2000. Ovarian carcinoma diagnosis. *Cancer* 89, No. 10: 1097-0142

Prevention, Risk and Hereditary Factors

Is there an association between Hormone Replacement Therapy and ovarian cancer?

The latest interpretation of data resulting from the Women's Health Initiative study suggests that postmenopausal women who take combined hormone replacement therapy (HRT) continuously may face a higher risk of ovarian cancer. While researchers say the findings shouldn't affect most women's decisions to take HRT to relieve moderate to severe menopausal symptoms, such as hot flashes, the possibility of an increased ovarian cancer risk support recently revised guidelines that call for the conservative use of hormone therapy.

Source: Anderson, G. *The Journal of the American Medical Association* (Vol 290:1739-1748).

Does the use of talc (talcum powder) as a feminine powder increases the risk of ovarian cancer?

A number of past studies found an increased risk of ovarian cancer from talcum powder use, but these studies were considered inconclusive because of limitations in the way data were collected and analyzed. More recent studies, such as one using data from Harvard University's Nurses' Health Study in 2000, find no overall risk of ovarian cancer from talc use and only a modest increase in one type of the disease – invasive serous ovarian cancer.

Source: Journal of the National Cancer Institute (Vol. 92, No. 3).

If a family member has ovarian cancer, can genetic screening determine if other family members will get the disease?

Approximately one out of every ten ovarian cancer cases is hereditary.

Most hereditary ovarian cancer can be attributed to two genes, BRCA 1 (breast cancer gene 1) and BRCA2 (breast cancer gene 2). Women who inherit a mutation in these genes are at greater risk of developing epithelial ovarian cancer. Lynch syndrome, which refers to a cluster of cancers that are related to a specific gene mutation, is also associated with increased risk of colorectal, uterine and ovarian cancer.

A thorough evaluation of family history (i.e., a history of breast, colon, or ovarian cancer) can identify women most likely to have a hereditary cancer risk, and genetic testing can determine if these mutations exist. Although having these mutations increases risk, it does not mean a woman will definitely get the disease. Furthermore, while genetic testing can indicate where there is increased risk and help determine appropriate monitoring, women should consider the psychological and possible insurance ramifications before proceeding with testing. Genetic counseling can help women determine whether they should be tested for genetic mutations linked with ovarian cancer.

Source: Cancer Control, July, 1999; Genet Test, 2000.

Is there any way to prevent ovarian cancer?

Currently there is no way of preventing ovarian cancer.

There are, however, several measures that have been found to reduce a woman's risk of developing the disease. Oral contraceptives can reduce the risk of ovarian cancer by fifty percent if taken for at least five years. Research has also shown that pregnancy and breast-feeding significantly reduce ovarian cancer risk. (Br. J. Cancer, March, 2001).

Tubal ligation and hysterectomy reduce risk, though researchers are unclear exactly how. Finally, prophylactic oophorectomy (removal of the ovaries) also reduces the risk. (Gynecologic Cancer Foundation Slide Presentation, 2000). Health professionals recommend that all options be discussed thoroughly with a physician.

What are ovarian cysts?

Ovarian cysts are fluid-filled sacs on the surface of the ovary that are quite common in women during their childbearing years. Most cysts result from the changes in hormone levels that occur during the menstrual cycle and the production and release of eggs from the ovaries. Most are harmless and go away on their own.

What is endometriosis? Can it cause ovarian cancer?

Endometriosis is a chronic and often progressive disease that develops when endometrial tissue, which normally lines the inner surface of the uterus, grows outside of the uterus. These implants occur most frequently in the pelvic region and on the reproductive organs but can appear in other areas, such as the bladder, as well.

In spite of the high prevalence of endometriosis in women the world over, researchers have been unable to determine its cause. Endometriosis can cause pain and scarring, and it is believed that 20 percent to 40 percent of women diagnosed with this chronic disease are infertile. (National Cancer Institute)

Researchers hypothesized that the most likely link between endometriosis and ovarian cancer is the association between endometriosis and infertility. It is well established that ovarian cancer risk is reduced with each pregnancy. Consequently, women who do not bear children, whether by choice or due to infertility issues, are believed to be at greater risk for ovarian cancer. (The Gynecologic Sourcebook, Third Edition)

Do fertility drugs increase your risk of developing ovarian cancer?

Use of fertility drugs does not increase a woman's risk of getting ovarian cancer. On the other hand, the scientists did find an association between ovarian cancer and certain causes of infertility itself, such as endometriosis.

"Some women who receive fertility treatments develop ovarian cancer because of underlying conditions that cause infertility, not because of the treatments themselves," said Roberta Ness, MD, MPH, of the University of Pittsburgh's School of Public Health.

Source: American Journal of Epidemiology (Vol. 155, No. 3: 217-224).

Is there a link between breast cancer and ovarian cancer?

Both breast and ovarian cancer can be caused by mutations in the BRCA1 (breast cancer gene 1) and BRCA2 (breast cancer gene 2) genes. Women with a family history of breast and ovarian cancer, or a personal history for either, particularly if diagnosed before age 50, should be aware of increased risk for the other. Women who have had breast cancer before the age of 50 are twice as likely to develop ovarian cancer, as are women who have not. (National Cancer Institute – What You Need To Know About Ovarian Cancer, 1998). Additionally, ovarian cancer has also been linked to colon cancer (via different genes).

Screening Tools, Detection and Treatment

Does an elevated CA 125 level always indicate that ovarian cancer is present?

Not always. Although a CA 125 blood test can be a useful tool for the diagnosis of ovarian cancer, in premenopausal women, it is not uncommon for a CA 125 count to be elevated due to benign conditions unrelated to ovarian cancer. Uterine fibroids, liver disease, inflammation of the fallopian tubes and other types of cancer can elevate a woman's CA 125 level. (ACOG Patient Education – 1996) The CA 125 test is more accurate in postmenopausal women. It is also important to note that in about 20% of cases of advanced stage disease, and 50% of cases of early stage disease, the CA 125 is NOT elevated, even though there is ovarian cancer present. As a result, the CA 125 is generally only one of several tools used to diagnose ovarian cancer. One of the most important uses of the CA 125 test, however, is to evaluate

progressive disease and tumor response in patients undergoing treatment, and to monitor the levels of women in remission for evidence of disease recurrence.

Is the blood marker LPA (lysophosphatidic acid) an effective screening tool for ovarian cancer?

LPA or lysophosphatidic acid is a substance that stimulates the growth of ovarian tumors. One small study found that levels of LPA in blood plasma are elevated in about 90% of women with early ovarian cancer. There are clinical trials going on presently to determine the effectiveness of LPA in detecting ovarian cancer. (JAMA, August 26, 1998) However, it is still too early to know if this test will be a good screening tool. This test is not yet available to the public.

Who is best trained to treat ovarian cancer?

Gynecologic oncologists. Research has shown that the five-year survival rate is greater when the initial surgery is performed by a gynecologic oncologist. (NCI) The initial surgery and staging of ovarian cancer is critical to determining the appropriate course of treatment, and ultimately survival outcomes. A gynecologic oncologist is an obstetrician gynecologist who is further trained in oncology to specialize in the diagnosis and treatment of women with gynecologic cancers. To find a gynecologic oncologist in your area, visit the Women's Cancer Network website at www.wcn.org and select "Find a Doc," or call 1-800-444-4441.

If there are no accurate screening tools, how is ovarian cancer diagnosed?

An exploratory surgical procedure called laparotomy is generally required for the definitive diagnosis of ovarian cancer. During this procedure, cysts or other suspicious areas must be removed and biopsied. After the incision is made, the surgeon assesses the fluid and cells in the abdominal cavity. If the lesion is cancerous, the surgeon continues with a process called surgical staging to ascertain how far the cancer has spread.

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Glossary of Medical Terms

As you progress through treatment, you may hear terms with which you are unfamiliar. This glossary lists some common words relating to ovarian cancer, as defined by the National Cancer Institute. For a more complete list, go to www.cancer.gov/dictionary

ascites (ah-SYE-teez)

Abnormal buildup of fluid in the abdomen.

assay (A-say)

A laboratory test to find and measure the amount of a specific substance.

Avastin (uh-VAS-tin)

Avastin is the brand name of a drug developed by Genentech. The drug is also called bevacizumab. Avastin, in combination with paclitaxel, pegylated liposomal doxorubicin or topotecan is approved by the FDA to treat platinum-resistant recurrent epithelial ovarian (prOC) in women who received no more than two prior chemotherapy treatments. Avastin is a type of antiangiogenesis agent that binds to a protein called vascular endothelial growth factor (VEGF).

BRCA1

A gene on chromosome 17 that normally helps to suppress cell growth. A person who inherits an altered version of the BRCA1 gene has a higher risk of getting breast, ovarian, or prostate cancer.

BRCA2

A gene on chromosome 13 that normally helps to suppress cell growth. A person who inherits an altered version of the BRCA2 gene has a higher risk of getting breast, ovarian, or prostate cancer.

CA-125

A substance that may be found in high amounts in the blood of patients with certain types of cancer, including ovarian cancer. CA-125 levels may also help monitor how well cancer treatments are working or if cancer has come back. Also called cancer antigen 125.

cancer

A term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body.

carboplatin-Taxol (KAR-boh-pla-tin-TAK-sol)

A chemotherapy combination used to treat endometrial, ovarian, head and neck cancers, and non-small cell lung cancer that has spread. It includes the drugs carboplatin and paclitaxel (Taxol). Also called Carbo-Tax regimen, carboplatin-Taxol regimen, CaT regimen, and PC regimen.

carcinoma in situ (KAR-sih-NOH-muh in SY-too)

A group of abnormal cells that remain in the place where they first formed. They have not spread. These abnormal cells may become cancer and spread into nearby normal tissue. Also called stage 0 disease.

cisplatin (sis-PLA-tin)

A drug used to treat many types of cancer. Cisplatin contains the metal platinum. It kills cancer cells by damaging their DNA and stopping them from dividing. Cisplatin is a type of alkylating agent.

CT scan

A series of detailed pictures of areas inside the body taken from different angles. The pictures are created by a computer linked to an x-ray machine. Also called CAT scan, computed tomography scan, computerized axial tomography scan, and computerized tomography.

debulking

Surgical removal of as much of a tumor as possible. Debulking may increase the chance that chemotherapy or radiation therapy will kill all the tumor cells. It may also be done to relieve symptoms or help the patient live longer. Also called tumor debulking.

differentiation

In cancer, refers to how mature (developed) the cancer cells are in a tumor. Differentiated tumor cells resemble normal cells and grow at a slower rate than undifferentiated tumor cells, which lack the structure and function of normal cells and grow uncontrollably.

distant cancer

Refers to cancer that has spread from the original (primary) tumor to distant organs or distant lymph nodes.

Doxil (DOK-sil)

A form of the anticancer drug doxorubicin that is contained in very tiny, fat-like particles. It may have fewer side effects and work better than doxorubicin. Doxil is used to treat ovarian cancer, AIDS-related Kaposi sarcoma, and multiple myeloma in patients whose disease has not gotten better after treatment with other anticancer drugs. It may be used together with other anticancer drugs. It is also being studied in the treatment of other types of cancer. Doxil is a type of anthracycline antitumor antibiotic. Also called Dox-SL, doxorubicin hydrochloride liposome, Evacet, LipoDox, and liposomal doxorubicin hydrochloride.

Emend

A drug used together with other drugs to prevent and control the nausea and vomiting caused by cancer treatment. It is also used to treat nausea and vomiting after surgery. It is a type of antiemetic and a type of substance P/neurokinin 1 receptor antagonist. Also called aprepitant.

endometrial cancer

Cancer that forms in the tissue lining the uterus (the small, hollow, pear-shaped organ in a woman's pelvis in which a fetus develops). Most endometrial cancers are adenocarcinomas (cancers that begin in cells that make and release mucus and other fluids).

epithelial ovarian cancer (eh-pih-THEE-lee-ul oh-VAYR-ee-un KAN-ser)

Cancer that occurs in the cells on the surface of the ovary. Also called ovarian epithelial cancer.

gemcitabine-cisplatin (jem-SY-tuh-been-sis-PLA-tin)

A chemotherapy combination used to treat malignant mesothelioma, advanced non-small cell lung cancer, advanced bladder cancer, advanced cervical cancer, pancreatic cancer, and epithelial ovarian cancer. It is also being studied in the treatment of other types of cancer. It includes the drugs gemcitabine hydrochloride and cisplatin. Also called gemcitabine-cisplatin regimen.

hysterectomy

Surgery to remove the uterus and, sometimes, the cervix. When the uterus and the cervix are removed, it is called a total hysterectomy. When only the uterus is removed, it is called a partial hysterectomy.

malignant ascites

A condition in which fluid containing cancer cells collects in the abdomen.

metastasis (meh-TAS-ta-sis)

The spread of cancer from one part of the body to another. Tumors formed from cells that have spread are called secondary tumors and contain cells that are like those in the original (primary) tumor. The plural is metastases.

Neulasta (noo-LA-stuh)

A drug used to increase numbers of white blood cells in patients who are receiving chemotherapy. It is a type of colony-stimulating factor. Also called filgrastim-SD/01 and pegfilgrastim.

Omentum (oh-MEN-tum)

A fold of the peritoneum (the thin tissue that lines the abdomen) that surrounds the stomach and other organs in the abdomen.

oophorectomy (oh-oh-foh-REK-toh-mee)

Surgery to remove one or both ovaries.

ovarian borderline malignant tumor/ovarian low malignant potential tumor

A condition in which cells that may become cancer form in the thin layer of tissue that covers an ovary (female reproductive gland in which eggs are made). In this condition, tumor cells rarely spread outside of the ovary.

ovarian cancer

Cancer that forms in tissues of the ovary (one of a pair of female reproductive glands in which the ova, or eggs, are formed). Most ovarian cancers are either ovarian epithelial carcinomas (cancer that begins in the cells on the surface of the ovary) or malignant germ cell tumors (cancer that begins in egg cells).

ovarian germ cell tumor

An abnormal mass of tissue that forms in germ (egg) cells in the ovary (female reproductive gland in which the eggs are formed). These tumors usually occur in teenage girls or young women, usually affect just one ovary, and can be benign (not cancer) or malignant (cancer). The most common ovarian germ cell tumor is called dysgerminoma.

ovaries

The pair of female reproductive glands in which the ova, or eggs, are formed and female hormones are produced. The ovaries are located in the pelvis, one on each side of the uterus. Each ovary is about the size and shape of an almond.

palliative therapy

Treatment given to relieve symptoms caused by advanced cancer. Palliative therapy does not alter the course of a disease, but improves the quality of life.

paclitaxel (PA-klih-TAK-sil)

A drug used to treat breast cancer, ovarian cancer, and AIDS-related Kaposi sarcoma. It is also used together with another drug to treat non-small cell lung cancer. Paclitaxel is also being studied in the treatment of other types of cancer. It blocks cell growth by stopping cell division and may kill cancer cells. It is a type of antimitotic agent. Also called Taxol.

Paraplatin (PAYR-uh-PLA-tin)

A drug that is used to treat advanced ovarian cancer that has never been treated or symptoms of ovarian cancer that has come back after treatment with other anticancer drugs. It is also used with other drugs to treat advanced, metastatic, or recurrent non-small cell lung cancer and is being studied in the treatment of other types of cancer. Paraplatin is a form of the anticancer drug cisplatin and causes fewer side effects in patients. It attaches to DNA in cells and may kill cancer cells. It is a type of platinum compound. Also called carboplatin.

PARP inhibitor

A substance that blocks an enzyme involved in many functions of the cell, including the repair of DNA damage. DNA damage may be caused by normal cell actions, UV light, some anticancer drugs, and radiation used to treat cancer. It may cause cancer cells to die. It is a type of targeted therapy. Also called poly (ADP-ribose) polymerase inhibitor.

PARP inhibitor AZD2281

A substance being studied in the treatment of breast, ovarian, and prostate cancers caused by mutations (changes) in the BRCA1 and BRCA2 genes. It is also being studied in the treatment of other types of cancer. It blocks an enzyme involved in many functions of the cell, including the repair of DNA damage. DNA damage may be caused by normal cell actions, UV light, some anticancer drugs, and radiation used to treat cancer. PARP inhibitor AZD2281 may cause cancer cells to die. It is a type of targeted therapy agent and a type of poly (ADP-ribose) polymerase inhibitor. Also called AZD2281 and olaparib.

peritoneal cavity (pare-i-toe-NEE-al)

The space within the abdomen that contains the intestines, the stomach, and the liver. It is bound by thin membranes.

peritoneal washing

This is a procedure where saline (salt solution) is introduced into the peritoneal cavity, and then removed by suction. After this, the fluid is examined for malignant (cancer) cells (called peritoneal washing cytology).

peritoneum (PAIR-ih-toe-NEE-um)

The tissue that lines the abdominal wall and covers most of the organs in the abdomen.

PET scan

A procedure in which a small amount of radioactive glucose (sugar) is injected into a vein, and a scanner is used to make detailed, computerized pictures of areas inside the body where the glucose is used. Because cancer cells often use more glucose than normal cells, the pictures can be used to find cancer cells in the body. Also called positron emission tomography scan.

polycystic ovary syndrome

A condition marked by infertility, enlarged ovaries, menstrual problems, high levels of male hormones, excess hair on the face and body, acne, and obesity. Women with polycystic ovary syndrome have an increased risk of diabetes, high blood pressure, heart disease, and endometrial cancer. Also called PCOS.

recurrent cancer

Cancer that has recurred (come back), usually after a period of time during which the cancer could not be detected. The cancer may come back to the same place as the original (primary) tumor or to another place in the body. Also called recurrence.

refractory cancer

Cancer that has not responded to treatment.

regional cancer

Refers to cancer that has grown beyond the original (primary) tumor to nearby lymph nodes and/or organs and tissues.

second-look surgery

Surgery performed after primary treatment to determine whether tumor cells remain.

Taxol

A drug used to treat breast cancer, ovarian cancer, and AIDS-related Kaposi sarcoma. It is also used together with another drug to treat non-small cell lung cancer. Taxol is also being studied in the treatment of other types of cancer. It blocks cell growth by stopping cell division and may kill cancer cells. It is a type of antimitotic agent. Also called paclitaxel.

topotecan

A drug used to treat certain types of ovarian cancer, lung cancer, and cervical cancer. Topotecan is a type of topoisomerase inhibitor. Also called Hycamtin and topotecan hydrochloride.

transvaginal ultrasound

A procedure used to examine the vagina, uterus, fallopian tubes, ovaries, and bladder. An instrument is inserted into the vagina that causes sound waves to bounce off organs inside the pelvis. These sound waves create echoes that are sent to a computer, which creates a picture called a sonogram. Also called transvaginal sonography and TVS.

tumor

An abnormal mass of tissue that results when cells divide more than they should or do not die when they should. Tumors may be benign (not cancer), or malignant (cancer). Also called neoplasm

Source: National Cancer Institute; Ovarian and Gynecologic Cancer Coalition/Rhonda's Club



Website Links For More Information:

American Cancer Society: www.cancer.org

American College of Obstetrics and Gynecology: www.acog.org

Foundation for Women's Cancer: www.wcn.org Enter your zip code to find a gynecologic oncologist

National Cancer Institute: www.cancer.gov

National Coalition for Cancer Survivorship: www.canceradvocacy.org

National Institutes of Health Clinical Trials: www.cancer.gov/clinicaltrials/search
or 1-800-422-6237

Ovarian Cancer National Alliance: www.ovariancancer.org

Ovarian and Gynecologic Cancer Coalition/Rhonda's Club: www.rhondasclub.org

SHARE: Self-Help for Women with Breast or Ovarian Cancer: www.sharecancersupport.org