Ovarian cancer is a type of cancer that starts in the ovaries. Each year, more than 22,000 people are diagnosed with ovarian cancer in the United States. There are no screening tests, and signs and symptoms of ovarian cancer can often be mistaken for other medical conditions.

This booklet can help you understand ovarian cancer and its treatment. It explains how the cancer is diagnosed and the ways in which it is treated. This booklet also provides information about where to find resources and support that can help you and your loved ones.
What Are the Ovaries, Fallopian Tubes, and Peritoneum?

The ovaries are part of the reproductive system. The female reproductive system usually has 2 ovaries, one on each side of the uterus. Each ovary is about the size of a walnut and has 3 parts:

- **The epithelium**—This covers the surface of the ovary and protects it.
- **The germ cells**—These cells produce the egg that is released each month. The egg travels through the fallopian tubes into the uterus. When fertilized, it can result in pregnancy.
- **The sex cord-stromal cells**—These cells produce sex hormones, such as estrogen.

Another part of the body near the ovaries and fallopian tubes is the peritoneum. This is a thin layer of tissue that lines the abdominal cavity. It also lines some of the organs in the abdomen and pelvis (the area of the body between the abdomen and the thighs). The cells of the peritoneum, fallopian tubes, and epithelium are all related and similar in appearance.

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**TALKING ABOUT OVARIAN CANCER**

**CA-125**: Ovarian cancer cells may produce a protein called CA-125. The CA-125 test can help show if the tumor is responding to treatment or if cancer has come back.

**GENETIC TESTING**: This test uses blood or saliva to look at your DNA and see if you inherited a mutation (a change in your genes). Mutations may increase your risk for ovarian or other cancers.

**BIOMARKER TUMOR TESTING**: This test looks at a tumor’s cells to see if there are mutations. This test can provide information about which treatments may work best for you.

**GYNECOLOGIC ONCOLOGIST**: This doctor treats cancers with medicine and surgery. They focus on cancers that start in female reproductive organs.

**MEDICAL ONCOLOGIST**: This doctor treats cancers with medicine.

**PLATINUM SENSITIVE OR RESISTANT**: Platinum drugs are a type of chemotherapy. If ovarian cancer comes back less than 6 months after a platinum treatment, it is platinum resistant. If it comes back more than 6 months later, it’s platinum sensitive.
What Are Ovarian, Fallopian Tube, and Peritoneal Cancers?

Cancer begins when a normal cell starts to grow out of control. When the cancer grows in the epithelial cells of the ovaries, it is called epithelial ovarian cancer. Because their cells are so similar, cancers of the fallopian tube and peritoneum are treated the same way as epithelial ovarian cancer. It is important to know that you can develop peritoneal or fallopian tube cancer even if you have had your ovaries removed.

When we talk about “epithelial ovarian cancer” in this booklet, we are including epithelial cancers of the ovaries, fallopian tubes, and peritoneum. The most important thing to know is that all three of these cancers are thought about and treated the same way.

Epithelial Cell Ovarian Cancer

Most—about 9 out of 10—of ovarian cancers start in epithelial cells.

High-grade serous adenocarcinoma is the most common type of epithelial ovarian cancer. (“Serous” cells line the epithelium.) It is seen in 7 out of every 10 people with epithelial ovarian cancer.

(This booklet focuses on treatment for high-grade serous ovarian cancer. Find resources for other types of ovarian cancer on the back page.)

OTHER TYPES OF EPITHELIAL OVARIAN CANCER

CLEAR CELL CARCINOMA: This is seen in 1 out of every 10 people with epithelial ovarian cancer. This type of ovarian cancer may be associated with a history of endometriosis. (Endometriosis is when the tissue that normally lines the uterus starts growing in places outside the uterus.)

ENDOMETRIOID ADENOCARCINOMA: This is another common type of epithelial ovarian cancer. This cancer is more often found at an early stage. It also can occur in people with a history of endometriosis.

MUCINOUS ADENOCARCINOMA: This kind of adenocarcinoma makes up 5% of all ovarian cancers. Its tumors are often filled with mucus and may become quite large.

LOW-GRADE SEROUS CARCINOMA: This is a rare, more slow-growing type of ovarian cancer. It is treated with surgery and often chemotherapy and/or hormone therapy.
Screening

There are currently no approved blood tests or scans used to screen for ovarian cancer in people at average risk for it. Some people are at high risk for ovarian cancer because they have a family history of ovarian cancer or have higher risk based on genetics. Doctors may recommend that these people have regular CA-125 blood tests and/or transvaginal ultrasounds. However, surgery to remove the ovaries and fallopian tubes before cancer has been detected has been the only method shown to reduce the risk of death. In people at average risk for ovarian cancer, CA-125 and ultrasounds are only done if there are signs or symptoms. (Page 15 lists general risk factors, and Page 8 lists signs and symptoms of ovarian cancer—“Let Others Know.”)

Diagnosis

If you have signs or symptoms of ovarian cancer, your doctor may do a:

- **Pelvic and rectal exam** (the doctor inserts fingers into the vagina and rectum to check the pelvis)—This is done to see if your ovaries are larger than normal.

- **Transvaginal or pelvic ultrasound** (sonogram)—For this test, the doctor inserts a small ultrasound wand into the vagina that can help them see the ovaries, fallopian tubes, and uterus.

- **CA-125 blood test**—Ovarian cancer cells may produce a protein called CA-125. Levels are sometimes higher than normal.

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**OTHER RARE TYPES OF OVARIAN CANCER**

**SEX CORD-STROMAL TUMORS:**
This type of cancer starts in the cells that produce hormones. About 7 out of every 100 ovarian cancers start in these cells. These tumors tend to be diagnosed in early stages and are often slow-growing. The most common type are granulosa cell tumors.

**GERM CELL TUMORS:** This type of cancer starts in the cells inside the ovary that produce eggs. These tumors are rare and often occur in those between the ages of 10 and 29.

**NEUROENDOCRINE TUMORS:**
These tumors include small cell cancers of the ovary. These cancers are rare, but often grow very quickly. You can learn more about this type of cancer at [www.smallcellovarian.org](http://www.smallcellovarian.org).
in people with ovarian cancer. CA-125 is not a perfect test and can be falsely elevated in other conditions even if you do not have ovarian cancer. That’s why it isn’t used as an ovarian cancer screening test. It’s also why your health care team may want to follow up its results with other tests.

- **CT scan**—For this test, you lie on a bed that moves through an x-ray tube to take pictures of your internal organs. The test may use a contrast dye. Let your doctor know if you have had an allergic reaction to contrast dye in the past.

If your doctor thinks you have ovarian cancer based on your symptoms, exam, scans, or ultrasound, you should ask for a referral to a gynecologic oncologist. This type of doctor specializes in the diagnosis and treatment of cancers that occur in the ovaries or other female reproductive organs. Any surgery to look for ovarian cancer should be done by a gynecologic oncologist. Studies have found that ovarian cancer patients are more likely to have a better outcome if their surgery is done by a gynecologic oncologist.

If you do not have a gynecologic oncologist in your town or city, consider traveling to a major medical center that has one. If needed, the gynecologic oncologist who does the surgery can refer you to a local doctor for the rest of your treatment. Before you decide on your treatment plan, you may want to get a second opinion from another gynecologic oncologist.

The only way to know if you do—or do not—have ovarian cancer is for a doctor to perform surgery or take a biopsy (a sample) of the tissue. The sample is then sent to a pathologist—a doctor who is an expert at studying cells—who will determine if it is ovarian cancer.

**Testing**

Once you have been diagnosed, there are two other types of tests your doctor will do to see what treatments will work best for you.

**GENETIC TESTS FOR HEREDITARY CANCER: TESTING YOUR GENES**

Every person diagnosed with ovarian cancer should receive genetic counseling and be offered genetic testing. Ideally, this would be done before you complete chemotherapy.

A genetic test that looks at your blood or saliva can tell if you inherited a mutation (a change in your genes) that increases your risk for ovarian cancer. About 1 in 10 people who are diagnosed with ovarian cancer were born with a hereditary cancer mutation. This type of mutation can also be passed on to children. This type of testing can be called genetic testing, germline testing, or testing for hereditary cancer.

The most common inherited mutation associated with ovarian cancer occurs in the BRCA genes. People who inherit a BRCA1 (breast cancer gene 1) or BRCA2 (breast cancer gene 2) mutation are at increased risk for both breast and ovarian cancer.
In a group of 100 people with ovarian cancer, about 10 to 15 people are likely to have a BRCA1 or BRCA2 mutation. You can be tested for only BRCA, or you can have a genetic test that also looks for other inherited mutations. A genetic counselor can review your family cancer history to help you decide which inherited mutations you should be tested for. These mutations could include:

- BRIP1
- RAD51C
- RAD51D
- BARD1
- PALB2
- STK11
- Genes linked to Lynch syndrome (MLH1, MSH2, MSH6, PMS2) or other family cancer syndromes

Talking to a genetic counselor before testing can help you understand your genetic testing options. Talking to a genetic counselor after testing can help you understand your results. If you have ovarian cancer, genetic testing is considered medically necessary and is covered by insurance. Knowing whether you have an inherited genetic mutation is important.

- It will tell you if you are at higher risk for any other cancers and possible ways to manage your risk.
- It will allow you to tell family members if they may be at higher risk for certain types of cancer so they can speak with a genetic counselor about testing.

- It will help your doctors know which treatments may work best for you.

**BIOMARKER TESTING: TESTING YOUR TUMOR**

Your doctor may also test your tumor. This can be called biomarker testing, tumor profiling, molecular testing, somatic testing, or genomic testing. Testing your tumor helps your doctor understand what is making the cancer grow and spread. Tumor testing may also identify certain clinical trials you can consider.

Testing your tumor for these biomarkers may help your doctor decide what treatment is right for you:

**BRCA:** Even if you are not born with a BRCA mutation, your cancer cells may develop one. So, even if your genetic tests showed you did not inherit a BRCA1 or BRCA2 mutation, your doctor will want to test your tumor for them. Knowing if you inherited a BRCA mutation or if your tumor developed one helps your doctor decide which treatments are best for you. Testing positive may mean a treatment called a PARP inhibitor may work for you after chemotherapy.

**HRD (HOMOLOGOUS RECOMBINATION DEFICIENCY):** If your tumor tests positive for HRD or LOH (loss of heterozygosity), a PARP inhibitor may be a treatment option.
**MSI-HIGH OR DMMR:** If your tumor tests MSI-high (MicroSatellite Instability-High) or dMMR (deficient MisMatch Repair), immunotherapy may be a treatment option.

Testing for multiple biomarkers is sometimes referred to as comprehensive biomarker testing, next generation sequencing, second generation sequencing, or massively parallel sequencing. There are a number of different companies that offer this kind of testing. Your doctor may recommend a specific company or test. The cost of these biomarker tests varies based on the type of insurance you have. Some companies offer financial assistance or payment plans.

**Treatment Planning**

Learning about your treatment options can feel overwhelming. You may not feel like you know what questions to ask your doctor or how to decide which treatment is “best.” Your treatment options will depend on:

- The type of ovarian cancer you have
- The stage of the cancer
- Your general health
- If you inherited a genetic mutation that increased your risk for ovarian cancer

- If your tumor has certain biomarkers that make it likely to respond to certain treatments

As you plan your treatment, two of the things you will want to consider are:

- What is the goal of each treatment? This may be a cure or it may be treatment to help you live longer with a good quality of life.
- What are the side effects of each treatment? You will want to know how the side effects may affect your quality of life, and what you and your health care team can do to help you manage them.

Try to prepare in advance for each doctor’s visit. Writing down a list of questions before any doctor’s visit can help you feel more organized and comfortable in asking questions and working with your doctor. Our [*Preparing for Your Doctor’s Visit worksheet*](www.CancerSupportCommunity.org/Ovarian-Cancer) can help you talk to your health care team about your goals for treatment, symptoms, side effects, and getting the emotional and practical support you need.

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**Open to Options®**

When facing a treatment decision, Cancer Support Community’s **Open to Options** program can help you prepare a list of personalized questions to share with your doctor to help decide which treatment is right for you. Call 888-793-9355 or find a Cancer Support Community or Gilda’s Club near you to make an **Open to Options** appointment.
SHONECE’S TIPS FOR LIVING WITH OVARIAN CANCER:

- Do not rely on the first diagnosis. Get a second opinion.
- Surround yourself with a strong support team.
- Research and join cancer support groups in your area.
- Develop and maintain a positive mental attitude. (Be your own advocate.)

LET OTHERS KNOW

There are several signs and symptoms of ovarian cancer. They are often overlooked because they may not seem like a big deal and can be caused by other health problems. They include:

- Bloating
- Pelvic or abdominal (belly) pain
- Trouble eating or feeling full quickly
- Feeling like you have to urinate (pee) right away or often
- Change in type or timing of your bowel movements

Tell a friend or family member to see a doctor if these symptoms:

- are new or unusual
- last for more than two weeks
- occur often (more than 12 times a month)
- are severe
- don’t respond to anything they would normally do to treat them, like changing their diet, getting more exercise, or resting
Clinical trials are research studies to test new treatments or learn how to use existing treatments better. While many trials focus on advanced ovarian cancer, there are also trials to improve early diagnosis, stop the cancer from coming back, reduce side effects, or improve quality of life. Clinical trials are the engine that drives progress in cancer treatment. In many instances, clinical trials offer the only way for you to get a new or experimental approach before it is approved for general use. If you enroll in a clinical trial, you will get:

- high quality treatment and care
- a chance to benefit from a new therapy
- an opportunity to help future ovarian cancer patients and contribute to ovarian cancer research

You can learn more about cancer clinical trials on the Cancer Support Community website: www.CancerSupportCommunity.org/ClinicalTrials

Surgery: Debulking and Staging

Surgery is one of the main treatments for ovarian cancer. During surgery, the gynecologic oncologist will remove as much of your cancer as possible. This is called debulking or cytoreduction. This usually includes removing one or both of your ovaries, the fallopian tubes, the uterus/cervix, the omentum (a fatty organ in the abdomen), biopsies of the peritoneum, and possibly some of the nearby lymph nodes. If the cancer has spread, other organs may also need to be removed. These could include parts of your bowel (small bowel or colon), spleen, liver, or, less likely, gallbladder, or parts of your stomach or urinary tract (bladder).

Surgery allows the gynecologic oncologist to stage your cancer. The stage explains how far the cancer has spread. This will help determine how your cancer is treated.

**STAGE I (1):** Cancer cells are found only in one or both ovaries.

**STAGE II (2):** The cancer has spread to another area of the pelvis, but has not spread to the abdomen.

**STAGE III (3):** The cancer has spread to the abdomen or lymph nodes.

**STAGE IV (4):** The cancer has spread beyond the abdomen to organs such as the lungs or liver.
WHAT DOES GRADE MEAN?

There are three grades of ovarian cancer: Grade 1, Grade 2, and Grade 3. The grade explains how fast the cells are growing. The lower the grade, the slower the growth. Low-grade serous epithelial cancer tends to be diagnosed in younger people and is slower growing. It is most often treated with surgery and often chemotherapy and/or hormone therapy. High-grade ovarian cancer is most often treated with surgery and chemotherapy.
Chemotherapy

Chemotherapy is the other main treatment for ovarian cancer. It may be given before or after surgery. Studies have found that overall survival may be the same whether the first treatment is chemotherapy or surgery. Your doctors will talk to you about which treatment approach they think is best for you.

Chemotherapy is typically given intravenously (using an IV). This can be through a vein in your arm or through a port, which is an IV that is placed under your skin in your upper chest. The port will stay in place during your entire treatment. It can be removed when it is no longer needed. Some chemotherapy drugs can also be given directly into the abdomen. This is called intraperitoneal (IP) chemotherapy. For this treatment, a port is placed in the upper abdomen and is used to put chemotherapy directly into the abdominal cavity.

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**FIRST CHEMOTHERAPY FOR NEWLY DIAGNOSED**

These are the latest types of treatments that have been approved as of July 2021. For the most updated information, please visit [www.CancerSupportCommunity.org/Ovarian-Cancer](http://www.CancerSupportCommunity.org/Ovarian-Cancer). Not all people get all side effects. Be sure to tell your health care team about the side effects you have.

<table>
<thead>
<tr>
<th>TYPE OF CHEMOTHERAPY</th>
<th>COMMON SIDE EFFECTS</th>
<th>WHAT TO KNOW</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PLATINUM-BASED</strong></td>
<td>Low blood counts</td>
<td>For most patients, their first chemotherapy treatment will be a platinum drug plus a taxane.</td>
</tr>
<tr>
<td></td>
<td>Thinning or brittle hair</td>
<td></td>
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<tr>
<td></td>
<td>Loss of appetite or weight</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Diarrhea</td>
<td></td>
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<tr>
<td></td>
<td>Nausea and vomiting</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Neuropathy (numbness, tingling, or pain in the hands or feet)</td>
<td></td>
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<tr>
<td></td>
<td>Taste changes</td>
<td></td>
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<tr>
<td></td>
<td>Hypersensitivity or risk of allergic reaction</td>
<td></td>
</tr>
<tr>
<td><strong>TAXANES</strong></td>
<td>Neuropathy (numbness, tingling, or pain in the hands or feet)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Low blood counts and risk of infection, bleeding, and fatigue</td>
<td></td>
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<tr>
<td></td>
<td>Hair loss</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fluid retention</td>
<td></td>
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<tr>
<td></td>
<td>Mild to moderate nausea</td>
<td></td>
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<tr>
<td></td>
<td>Nail and skin changes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dry eye or loss of natural tears</td>
<td></td>
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<tr>
<td></td>
<td>Risk of allergic reaction</td>
<td></td>
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<tr>
<td></td>
<td>Flu-like symptoms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Joint pain</td>
<td></td>
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<tr>
<td></td>
<td>Weakness</td>
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</tbody>
</table>
These are the treatments that have been approved as of July 2021. Others are in clinical trials. Visit www.CancerSupportCommunity.org/Ovarian-Cancer for specific drugs and the most up-to-date lists.

### CHEMOTHERAPY

<table>
<thead>
<tr>
<th>COMMON SIDE EFFECTS</th>
<th>WHAT TO KNOW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nausea and vomiting</td>
<td>• Loss of appetite and weight loss</td>
</tr>
<tr>
<td>Diarrhea or constipation</td>
<td>• Dry eye</td>
</tr>
<tr>
<td>Low blood counts and risk of infection, bleeding, and fatigue</td>
<td>• Risk of allergic reaction</td>
</tr>
<tr>
<td>Neuropathy (numbness, tingling, or pain in the hands or feet)</td>
<td>• Flu-like symptoms</td>
</tr>
<tr>
<td>Hair loss</td>
<td>• Joint pain</td>
</tr>
<tr>
<td>Fluid retention</td>
<td>• Weakness</td>
</tr>
<tr>
<td>Nail and skin changes</td>
<td>• Mouth sores</td>
</tr>
<tr>
<td>Hair loss</td>
<td>• Fever</td>
</tr>
<tr>
<td>Fluid retention</td>
<td>• Fatigue</td>
</tr>
<tr>
<td>Nail and skin changes</td>
<td>• Skin rash</td>
</tr>
<tr>
<td>Loss of appetite and weight loss</td>
<td>• Using certain chemotherapy drugs may cause a loss of fertility. Talk with your health care team if this is a concern for you.</td>
</tr>
<tr>
<td>Hair loss</td>
<td>• Some types of chemotherapy can increase the risk of heart problems. You may have to switch to a different chemo or get an additional medicine to help protect your heart.</td>
</tr>
</tbody>
</table>

### TARGETED THERAPY

<table>
<thead>
<tr>
<th>COMMON SIDE EFFECTS</th>
<th>WHAT TO KNOW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weakness or dizziness</td>
<td>• Blocks the growth of the blood vessels tumors need to thrive</td>
</tr>
<tr>
<td>Pain</td>
<td>• May help keep cancer cells from repairing their damaged DNA, causing them to die</td>
</tr>
<tr>
<td>Nausea &amp; vomiting</td>
<td>• Low white blood cell count and risk of infection and bleeding</td>
</tr>
<tr>
<td>Loss of appetite and weight loss</td>
<td>• Hair loss</td>
</tr>
<tr>
<td>Constipation or diarrhea</td>
<td>• Mouth sores</td>
</tr>
<tr>
<td>Upper respiratory infection or difficulty breathing</td>
<td>• Headache</td>
</tr>
<tr>
<td>Kidney problems</td>
<td>• Bleeding problems</td>
</tr>
<tr>
<td>Low white blood cell count and risk of infection and bleeding</td>
<td>• High blood pressure</td>
</tr>
</tbody>
</table>

### IMMUNOTHERAPY

<table>
<thead>
<tr>
<th>COMMON SIDE EFFECTS</th>
<th>WHAT TO KNOW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diarrhea or constipation</td>
<td>• Keeps tumor cells from hiding from your immune system</td>
</tr>
<tr>
<td>Cough</td>
<td>• An option if your tumor tests MicroSatellite Instability (MSI)-high</td>
</tr>
<tr>
<td>Decreased appetite</td>
<td>• Infection or swelling around the lungs</td>
</tr>
<tr>
<td>Fatigue</td>
<td>• Nausea</td>
</tr>
<tr>
<td>Fever</td>
<td>• Pain in muscles, bones, joints, or stomach</td>
</tr>
<tr>
<td>Hair loss</td>
<td>• Shortness of breath</td>
</tr>
<tr>
<td>Headache</td>
<td>• Skin rash or itching</td>
</tr>
<tr>
<td>Infection or swelling around the lungs</td>
<td>• Urinary tract infection</td>
</tr>
<tr>
<td>Nausea</td>
<td>•</td>
</tr>
<tr>
<td>Pain in muscles, bones, joints, or stomach</td>
<td>•</td>
</tr>
</tbody>
</table>
Neoadjuvant Chemotherapy
Treating stage III (3) C or stage IV (4) cancer with chemotherapy before surgery may help control it better or make surgery less extensive.

Debulking surgery
Adjuvant Chemotherapy

Evaluate for evidence of cancer

Evidence of cancer
Maintenance therapy to slow or stop the cancer's growth

No evidence of cancer
Maintenance therapy to keep cancer from returning

No additional treatment

No recurrence
Recurrence (less than 6 months)
Tumor is platinum-resistant
Treatments can include chemotherapy, targeted therapy, clinical trials, and immunotherapy.

Recurrence (after 6 months)
Tumor is platinum-sensitive
Treatments can include chemotherapy, targeted therapy, clinical trials, and immunotherapy.

● Routine CA-125 tests and scans to see if the cancer starts growing again
● Testing your tumor for biomarkers that can guide treatment choices
Maintenance Therapy

After you complete your chemotherapy treatment, your doctor may recommend maintenance therapy. Maintenance therapy is used to stop or slow your cancer’s growth or to prevent it from coming back. Chemotherapy and targeted therapy can be used as maintenance therapy to treat ovarian cancer.

Looking For Recurrence

Your doctors will monitor you closely after you finish treatment. You may have a CA-125 blood test if your CA-125 levels were higher than normal when you started treatment. If needed, your doctor may also have you come in for scans to see if the cancer has come back or is no longer being controlled by the treatment you are on.

- If the cancer comes back in less than 6 months, your cancer is **platinum-resistant**. This means you will probably not be treated with any other platinum therapies.

- If the cancer comes back in more than 6 months, your cancer is **platinum-sensitive**. This means you are likely to be treated again with platinum-containing therapies.

Your health care team may recommend other treatments if your cancer comes back.

- **Targeted therapy** “targets” a specific change in some cancers that help them grow, divide, and spread. Doctors decide to use it based on the findings of biomarker tests.

- **Immunotherapy** is a type of cancer treatment that uses the body’s natural defenses to identify, attack, and kill cancer cells. The immune system is designed to attack any cell it sees as unhealthy or abnormal.

Immunotherapy treatments help fight cancer in three ways: They boost the immune system, “mark” cancer cells so that your immune system can better find and destroy them, and help the immune system find cancer cells and deliver treatment directly to them. It may be an option if you have certain biomarkers.
GENERAL RISK FACTORS

Studies have found that these factors increase risk for ovarian cancer:

- Age: Risk increases as you get older
- Weight: Having had obesity in early adulthood increases your risk
- Ethnicity: Risk is higher among North American, Northern European, and Ashkenazi-Jewish people
- Having endometriosis
- Not having a child until age 35, not being able to have a child, or never having a child
- Having a family history of ovarian, breast, or colorectal cancer on your mother’s or your father’s side of the family
- Having had breast cancer

QUESTIONS TO ASK YOUR HEALTH CARE TEAM

1. What type of ovarian cancer do I have?
2. What is my stage?
3. What is my prognosis?
4. What are my treatment options?
5. Who will be the members of my health care team?
6. When should I have genetic testing?
7. Should I have my tumor tested for any biomarkers?
8. What is the goal of the treatment I am on/you are offering me?
9. How long will my treatment last?
10. What kind of side effects may I have and how can I manage them?
11. How might treatment affect my sex life?
12. What support services are available to me and my family?
13. Who on the health care team should I contact with questions and issues? How do I contact them after hours?
14. How much is this treatment going to cost me?
15. How can I get help managing the cost of my cancer care? Is there a social worker or financial counselor I can talk to?
Managing Side Effects

Ovarian cancer and its treatments can cause a range of side effects. The most common include: hair loss, nausea and vomiting, bone marrow suppression (this includes anemia, weakening of the immune system, or risk of bleeding), nerve pain (neuropathy), fatigue, diarrhea or constipation, swelling of limbs (lymphedema), and difficulty with sex and intimacy.

Before your treatment begins, talk to your doctor about the types of side effects that you may experience and how you can manage them. You can also ask your doctor for a referral to a palliative care specialist at any point during or after treatment. Palliative care is not the same as hospice. Palliative care is supportive care that aims to improve your quality of life. Palliative care can also help your loved ones.

After you start treatment, keep track of how you feel. Write down when you notice a problem, how long it lasts, and if there is anything that makes it better. Don’t be afraid or embarrassed to tell your doctors what is going on with your body. Talking to your health care team is key to finding options for coping with these side effects. Our Preparing for Your Doctor’s Visit worksheet (see www.CancerSupportCommunity.org/Ovarian-Cancer) can help you talk to your health care team about your goals for treatment, symptoms, side effects, and getting the emotional and practical support you need.

Eating Well During and After Treatment

Eating well can help make it easier for you to get through treatment and feel better. But this isn’t always easy. Nausea, vomiting, a decrease in appetite, diarrhea, or fatigue may make you not want to eat anything at all. And when you have many medical appointments, it can be easy to skip meals. But you need to eat to keep your strength up. Also, if you are taking medications, not eating can cause the nausea you are trying to avoid. It’s also important to make sure you are drinking enough water or other fluids.

It may help to not eat foods with strong odors. Food that is cold often has less of an odor and may be easier to manage. Eating bland foods that are high in calories and protein and eating small amounts often during the day, instead of three larger meals, can also be helpful. Try to avoid fried, greasy, spicy, and overly sweetened foods. These often make people nauseated. Supplement drinks may be an option if eating is difficult, but you should talk to your health care team before you start drinking them.

A dietitian or a palliative or supportive care specialist can help you learn new ways to manage side effects and eat well during and after treatment. For recipes and more hints and tips on eating well during treatment, see www.CancerSupportCommunity.org/TreatmentNutrition.
Getting Support

Cancer stirs up many feelings. It affects you, your family, and your loved ones. It is normal to feel sad, anxious, worried, shocked, stressed, or panicked. Remember that cancer can affect anyone. And every person who has cancer deserves good care and support.

Tips for Coping

- Ask your health care team questions. Keep asking questions if there is something you don’t understand.
- Know what signs or symptoms you should tell your care team about right away. Know how to contact your care team during and outside of business hours.
- Control what you can. If you smoke, get help to stop. Find out what type of exercise you can do and how often. Eat healthy foods and try to maintain a healthy weight.
- Know that you will be more anxious when it gets close to a doctor’s appointment. Be gentle with yourself when you are feeling stressed.
- Ask for help from friends and your community, or ask your caregiver to do so. The Cancer Support Community’s MyLifeLine.org is a great way to coordinate this online.
- Contact the patient groups on the back page to find local and online support groups, helplines, and other ways to get support from others facing ovarian cancer.
- Ask your health care team about resources for social, emotional, and practical support.
- If you search for information online, make sure you are using trusted websites. Turn to the back page to see a listing of trusted patient groups.

Find the Support You Need

- Share your feelings with friends, family members, a counselor, or a clergyperson.
- A counselor or therapist can help you with anxiety. Other things that can help are yoga, breathing, and relaxation exercises.
Caregivers

Caregiving for a loved one can take different forms. It might involve physical care or emotional support. Some caregivers assist with money matters, insurance, household chores, rides, or making appointments.

Caregiving can be a full-time job. A caregiver with another job may miss days of work or have trouble getting work done. Some caregivers take unpaid leave, turn down promotions, or lose benefits. It can be very stressful to care for someone and worry about keeping your job at the same time. Caregivers may be able to use the Family Medical Leave Act (FMLA) to ask for protected time off work.

Caring for someone who has cancer is not easy. Caregivers are often very focused on their loved one. They may neglect their own health and well-being. It is important for caregivers to take care of themselves. They also need support and help from family, friends, and the health care team. Many caregivers benefit from support groups. They can talk about emotional issues, share concerns, obtain help, and feel less alone. To learn more, visit www.CancerSupportCommunity.org/Caregivers.

Donna’s Experience

Donna finds hope in the treatment advances that are being made through cancer clinical trials. More than seven years ago, Donna was diagnosed with low-grade serous ovarian cancer. Her particular cancer did not respond well to chemotherapy, so Donna’s doctors recommended that she consider joining a clinical trial. For Donna, it was a decision that came without hesitation. “It was pretty clear that the chemo wasn’t working,” she says. “The clinical trial gave me hope that I might find a treatment that works for me.”

After staying in that clinical trial longer than anyone else, Donna had a partial response to the treatment. Since then, she had a recurrence that was treated with surgery. Today she is facing another recurrence. Her health care team first treated it with several rounds of chemotherapy, but now she is joining a worldwide precision medicine clinical trial this winter.

Donna knows that as a patient, it is important to be as informed as possible about your cancer and its treatment. “Keep learning,” she says, and “talk to your oncologist.” She admits, “Ovarian
cancer is very, very scary. When I was first diagnosed, I thought I had a year to live.” What she has learned since then is that “medicine is still very much an art form. We have a long way to go. You have to go through the journey. And it’s a process.”

To help deal with a cancer diagnosis and treatment, Donna tries to remain fit. In addition to watching her diet, she stays active by walking 3 miles 4 times a week and by spending time with her 3 granddaughters. “I keep very, very busy,” she says.

Also, “it’s really important to connect with other people.” Joining a group with people who’ve gone through a similar journey can be helpful. They can offer emotional support and provide other points of view on treatment. With other ovarian cancer survivors, she also talks to students: “We tell our stories. Maybe some good will come out of it.”

As an active member of your health care team, you will work closely with your doctors in order to make the best possible decisions for you. Donna says that while she doesn’t spend all her energy on her cancer, “I certainly do my homework. I’m very well aware that the research for the rarer kinds of cancer doesn’t get the attention or possibilities for treatment. You have to be as on top of it as you can. You have to be an advocate as much as you can.”
Resources for Ovarian Cancer Information & Support

The Clearity Foundation • 858-657-0282 • www.clearityfoundation.org
Facing Our Risk of Cancer Empowered (FORCE) • 866-288-7475 • www.facingourrisk.org
Livestrong Fertility • 855-844-7777 • www.livestrong.org/what-we-do/program/fertility
National Cancer Institute (NCI) • 800-422-6237 • www.cancer.gov
NCI's Clinical Trials Registry • 888-422-6237 • www.cancer.gov/clinicaltrials
Ovarian Cancer Research Alliance • 212-268-1002 • www.ocrahope.org
Penn Medicine Abramson Cancer Center Telegenetics Program • 800-789-7366 • pennmedicine.org/telegenetics
Steps Through • 866-830-5134 • stepsthrough.org

Cancer Support Community Resources

The Cancer Support Community’s (CSC) resources and programs are available free of charge. Call 888-793-9355 or visit www.CancerSupportCommunity.org for more info.

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC’s toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs at www.CancerSupportCommunity.org/FSAC.

MyLifeLine — CSC’s private, online community platform allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda’s Club. www.CancerSupportCommunity.org/FindLocation

Services at Local CSCs and Gilda’s Clubs — With the help of 170 locations, CSC and Gilda’s Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

FRANKLY SPEAKING ABOUT CANCER: OVARIAN CANCER THANKS ITS PROGRAM PARTNERS:

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The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

This booklet is available to download and print yourself at www.CancerSupportCommunity.org/Ovarian-Cancer. For print copies of this booklet or other information about coping with cancer, visit Orders.CancerSupportCommunity.org.

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