# OVARIAN CANCER

DVD

featuring

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Olympic Gold Medalist and Cancer Survivor









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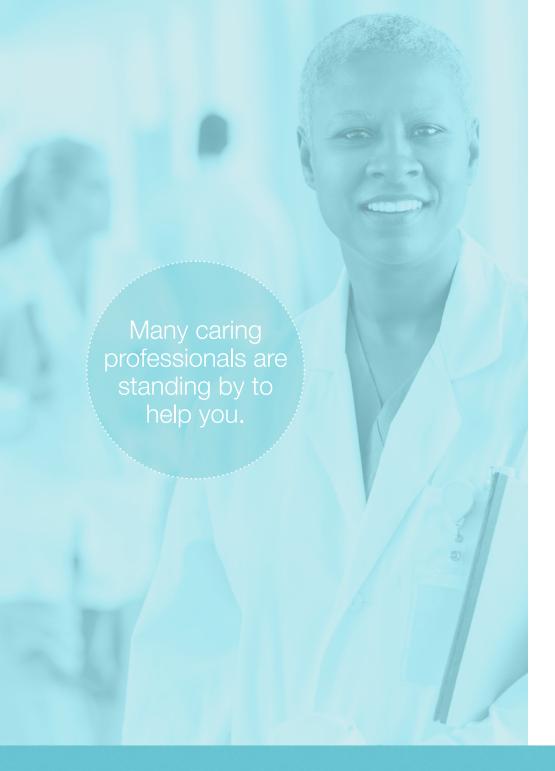
#### DVD inside back cover:

The Understanding Ovarian Cancer DVD (15 min) features the stories of two patients, with expert commentary from doctors who specialize in ovarian cancer treatment. Shannon Miller shares her own experience with ovarian cancer.

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# Introduction

Learning that you have been diagnosed with ovarian cancer can be difficult. Cancer is scary! It can also be hard to absorb all of the information you might be getting. So it's important to keep a few key ideas in mind:

- You are not alone—many women have been through this, and many caring professionals are standing by to help.
- There is hope—ovarian cancer can be treated many ways. The survival rate for women with ovarian cancer has been increasing steadily.
- Take a breath—you don't have to learn everything today.
   Take time to talk, read, and think.
- It's OK to ask questions—even lots of questions! Your doctors want to help, and they want you to understand as much as you can. If you or a loved one does not speak English, or is not comfortable with English, ask for an interpreter.

This booklet and DVD program will help you better understand ovarian cancer, how it can be treated, and how you can make changes to improve your health and well-being.



# About Ovarian Cancer

In 2014, about 22,000 women in the United States were diagnosed with ovarian cancer.

About half of the women diagnosed with this type of cancer are 63 years or older. It is more common in white women than African-American women, although the 5-year survival rate is lower for African-American women than for white women.

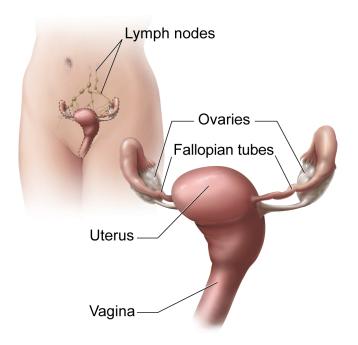
Ovarian cancer happens when cells in one or both of a woman's ovaries start growing in an out-of-control way. Ovarian cancer should not be confused with other types of growths that can occur on the ovaries.

For example, it is very common for younger women to have *cysts* on an ovary. Cysts are fluid-filled sacs that are *not* cancerous. Cysts can be quite large, and may cause symptoms, but they are not life-threatening. Cysts are usually removed surgically.

22,000 women in the United States were diagnosed with ovarian cancer in 2014.

Unlike cysts, *tumors* are solid growths. Some tumors grow and may produce symptoms, but they do not contain cancer cells that could spread to other parts of the body. These kinds of tumors can also be removed surgically and are not life-threatening.

Ovarian cancer tumors can take different forms, depending on which type of tissue the cells affect. Not only does cancer form tumors, the cancer cells can break away from the tumor and spread to other parts of the body.





## Risk Factors for Ovarian Cancer

All women have some risk of ovarian cancer. On average, 1 in every 72 women will be diagnosed with ovarian cancer in their lifetime. But some women have a higher risk than others.

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The following can *raise* the risk of getting the most common types of ovarian cancer:

- Older age (age 63 and older)
- Obesity
- Use of estrogen replacement therapy after menopause
- Having a blood relative who had ovarian, breast, or colorectal cancer
- Inherited genetic factors (but note that most cases of ovarian cancer occur in people with no family history of the disease and no genetic risk).
- Having a personal history of breast cancer



On the other hand, some things *lower* the risk for getting ovarian cancer, including:

- Pregnancy (women who have carried a baby full-term have a lower risk of ovarian cancer than women who have not)
- Use of birth control pills or contraceptive injections (risk is lower in women who have used birth control pills for at least 3-6 months, and lower in women who used a contraceptive injection for 3 or more years)
- Tubal ligation (having your "tubes tied")
- Hysterectomy (having your uterus removed)

Only after ovarian cancer has been growing for some time will a woman notice symptoms.





When ovarian cancer starts to grow, it doesn't always cause symptoms. But ovarian cancer may cause the following symptoms:

- Bloating
- Pelvic or abdominal pain
- Difficulty eating or feeling full quickly
- Needing to urinate frequently, or feeling the urge to do so

Less common symptoms of ovarian cancer include:

- Fatigue
- Indigestion
- Back pain
- Pain with intercourse
- Constipation
- Changes in the menstrual cycle ("periods")

Of course, these are very general symptoms. Many women have some of these symptoms from time to time, but that does not mean they have ovarian cancer. Only if the symptoms are new, occur almost daily, and last for more than 2–3 weeks might they suggest something serious, such as ovarian cancer.





# Diagnosing Ovarian Cancer

If you or your doctor thinks you might have ovarian cancer, tests will be used to confirm the diagnosis. Ultrasound or x-ray tests can reveal if there is a tumor on one or both ovaries, though they cannot tell if the tumor is cancer. Blood tests can show if you have the right number of the different kinds of blood cells.

The tests may also look for a protein called CA-125, which may be higher than normal in some women with ovarian cancer.

Your doctor may obtain a small tissue sample from a tumor, called a biopsy, to determine if the tumor is cancer. This information will be combined with results from other tests to determine the stage of the cancer.

Ovarian cancer is classified by how far the disease has spread. Stage I (1) is the earliest and most easily treated type of cancer. In Stage II (2), the cancer has spread to other organs, such as the uterus, within the pelvic region. Stage III (3) is when the cancer spreads to other areas within the abdomen, including nearby lymph nodes. Stage IV (4) is when the cancer has spread beyond the ovaries to other parts of your body, such as the lungs or liver. Not all patients with ovarian cancer have the same pattern of spread. Cancer staging information allows your health care provider to give you a personal treatment recommendation.

#### STAGE I



Cancer is confined to one or both ovaries.

#### STAGE II



Cancer spreads within the pelvic region.

#### STAGE III



Cancer spreads to other body parts within the abdomen.

#### STAGE IV



Cancer spreads beyond the abdomen to other body parts.





# **Treatment Options**

There is no one-size-fits-all treatment for ovarian cancer. Treatments are usually tailored for your specific cancer type, cancer stage, how healthy you are, and whether you plan to have children. The treatment—or treatments—may also change with time, depending on how well they are working.

Different treatments can be tried if an existing treatment is either not working or causes intolerable side effects. The following are summaries of the major ways that ovarian cancer can be treated.

#### Surgery

Surgery is the main treatment for most ovarian cancers. What type of surgery you have, and when you have it, depend on many factors such as the location of the tumor and how far the cancer has spread. For women with certain kinds of tumors found at a very early stage, it may be possible to remove the cancer without taking out both ovaries and the uterus.

Surgery to determine how far cancer has spread is called *staging surgery*. Surgery to actually remove an ovarian tumor is called *debulking*. In order to debulk the cancer, the surgeon may need to remove parts of other organs as well. If both ovaries and/or the uterus are removed, a woman will not be able to become pregnant. It also means she will enter menopause and may experience symptoms such as hot flashes, night sweats, changes in her sex drive, and vaginal dryness.



#### Chemotherapy

Chemotherapy uses medicines that kill rapidly dividing cells. Most cells in your body do *not* divide rapidly, so the medicines target the fast-dividing cancer cells. But cells in certain parts of the body, such as the mouth and scalp, *do* divide rapidly. If these cells are killed by chemotherapy, you may experience side effects such as hair loss and mouth sores. Most side effects disappear once treatment is stopped. For example, hair will grow back, although it may look different.

Your cancer team will discuss the risks of side effects with you, as well as ways to help manage them if they occur. Chemotherapy is usually given in cycles, with each period of treatment followed by a recovery period. There are many kinds of chemotherapy drugs, which can be used in different combinations to fight ovarian cancer. These medicines can be taken in different ways: as pills, infused into a vein, or infused into the abdomen.

#### **Targeted Therapy**

Targeted therapy is a newer type of cancer treatment that kills (or "targets") specific kinds of cancer cells. Like keys that fit into locks, these therapies zero in on specific molecules that promote tumor growth and spread. Each type of targeted therapy works differently. Some change the way a cancer cell grows, while others stop cancer cells from dividing or repairing themselves. Your health care provider can

help you decide if a targeted therapy

would be right for you.

#### **Clinical Trials**

An option for some women with ovarian cancer is to get involved in a clinical trial. Clinical trials are carefully controlled studies of new ways to treat diseases. Some of these studies have been specifically designed for patients with ovarian cancer.

There is no guarantee that a new treatment will help, but for some patients, a clinical trial may be the best treatment option available. By participating in a clinical trial, you may help both yourself and future patients like you. If you are interested in a clinical trial, talk to your health care provider or visit clinicaltrials.gov.



# What About Genetic Testing?

Genetic testing should be a part of managing your ovarian cancer. Sometimes the results from a genetic test may help your health care providers choose treatments that are right for you.

A small sample of blood or saliva can be tested to see if you

carry genes that might affect your risk of cancer or

suitability for certain cancer treatments. It usually takes about a month to get the results back.

Two important genes related to ovarian cancer are called *BRCA1* and *BRCA2*. These genes normally help prevent certain types of cancer. If they don't work properly, your cancer risk rises.

Other genes may be involved with ovarian cancer as well. Your health care provider can help you decide whether to test for these other genes. Before getting any kind of genetic test, talk to your health care provider or a genetic counselor.

If you have a family history of breast and/or ovarian cancer, testing for *BRCA1* or *BRCA2* or for other genes (called "multigene testing") may help determine your own risk of developing these cancers. If you have already had breast or ovarian cancer, this testing may help determine if you have an increased risk for other cancers.

If you have a *BRCA1/2* mutation, you have a variety of options for reducing your risk of future cancer, including more frequent cancer screenings, surgery, or the use of medicines or hormone therapies.



Another set of genetic mutations that can raise a woman's risk of ovarian cancer are those related to Lynch syndrome, which is also called hereditary nonpolyposis colon cancer. A variety of mutations can cause this syndrome, which also raises the risk of colon and other types of cancer. Tests are available that can show whether a woman has any of the mutations known to be connected to Lynch syndrome.

If your health care provider does not bring up the issue of genetic testing, ask him or her about it.

#### Some questions you might ask:

- What could I learn about my risks by having genetic testing?
- Would having genetic testing help any of my family members better understand their risks of ovarian or other cancers?
- Could genetic testing help guide my treatment?



# Talking With Your Doctors

Good communication is a key part of getting good health care. Your doctor and health care team will try to answer all of your questions and help you sort out the information about your diagnosis. But you need to do your part by asking questions and making sure you understand what you are being told. It might be helpful to write down questions when you think of them and bring the list with you to your next appointment.

Because it can be hard to remember things when you are feeling tense or upset, it may be helpful to bring a friend or family member along to take notes during visits to your health care provider. It may also help to keep a chart of your treatment options with pros and cons related to your specific situation.

In general, be open and honest about physical or emotional issues—that's the best way to get the help you want.





### Your Treatment Team

Here are some of the health professionals who may be part of your cancer treatment team.

Gynecologic oncologists are doctors who specialize in treating cancer of the female reproductive organs and should be the primary health care providers for those who have has ovarian cancer.

Medical oncologists are doctors who specialize in diagnosing and treating cancer and should refer women with ovarian cancer to a gynecologic oncologist.

**Radiation oncologists** are experts in treating cancer using radiation.

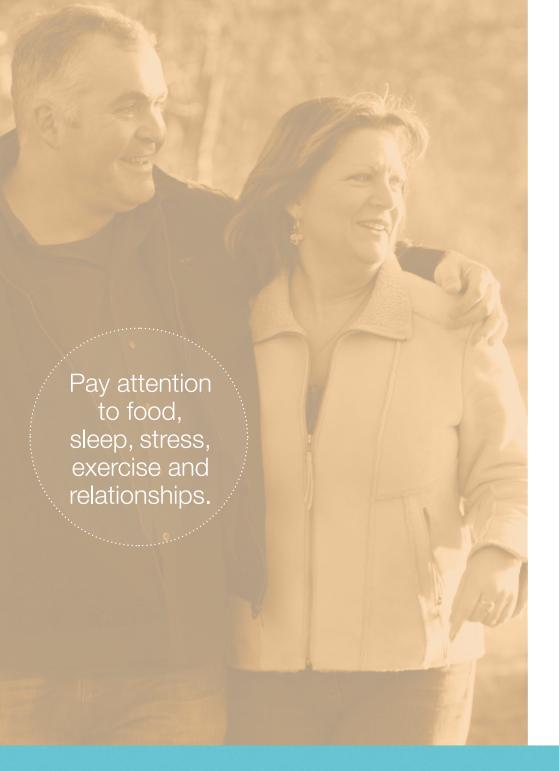
Gynecologic oncology clinical nurse specialists are registered nurses with advanced training in the care of people with gynecologic cancer.

Oncology nurse practitioners are registered nurses trained in cancer care who can also prescribe treatments.

**Genetic counselors** are certified health professionals with specialized graduate training in helping people understand their genetic risks for diseases.

Physician assistants work directly under the supervision of a physician to help care for patients. They often are able to prescribe medications, although this varies from state to state.







# Staying Healthy

Going through treatment for ovarian cancer can be hard, but there are many steps you can take that may help. Paying attention to what you eat, getting enough sleep, reducing stress, staying active, and maintaining your close relationships are all important. Each person, and each situation, is different, so tailor the following suggestions to meet your own needs and goals.

Eat a diet recommended by your doctor.
Cancer or cancer therapies can change your appetite or make eating difficult.
Some cancer therapies can cause mouth sores, so it is important to maintain good oral hygiene. Talk to your oncology team about ways to help manage this side effect.

You also may need to change your diet to avoid unwanted changes in your weight. Avoid "fad" diets and unproven supplements. Always consult your health care provider before taking any herbal products or supplements, because they may interact with your cancer therapy.

LINDERSTANDING OVARIAN CANCER

# Cancer and its treatment can affect both the mind and the body.

Work with your health care team to understand how exercise may fit into your management plan. Exercise can be good for both your body and your mind.

Pay attention to your moods. Cancer and its treatment can affect both the mind and the body. Of course, it's normal to feel a range of emotions when faced with ovarian cancer. But severe emotions, such as anxiety and depression, can make it harder to stay healthy. Tell your health care provider about your moods. There are many ways to reduce anxiety, relieve depression, and treat other kinds of emotional troubles.





# Finding Support

Having cancer can be stressful and exhausting.

Don't be afraid, or embarrassed, to ask for help if you need it. Try to build a support network—a group of people you can turn to when you need it. People around you often want to help, but they may not know how unless you ask them.

It's also important to have at least one person to whom you can tell anything. Although this might be a spouse or partner, it may not be—sometimes the thing you most need to talk about is your spouse or partner, so having somebody else as a "confiding relationship" can be important.

Sometimes those around you want to help so much that they give unwanted advice or don't stop to just listen. It can be helpful to remind people that sometimes what you need is to just talk, without having the other person try to fix a problem or suggest solutions. And sometimes you may simply be tired or irritable and not be in a mood to talk at all. If you are clear with people about your needs and the reality you are facing, chances are they will appreciate your honesty and try to adapt to your needs as much as possible.



Another support option is to reach out to "professional helpers" such as social workers, nurses, or spiritual leaders. Your health care provider may offer a referral to professionals who are familiar with the needs of cancer patients. These professionals can help you with housing needs, child care, transportation, or navigating the health care system. Take advantage of this support if possible. Refer to the resources in the back of this booklet for organizations that can help.

It can also be comforting and helpful to meet others who are coping with cancer. Cancer support groups can meet in person, by phone, or over the Internet via dedicated Web sites, blogs, or social media such as Facebook or Twitter. You may gain new insights, get new ideas for ways to cope, or feel better just knowing you're not alone. It may also help to seek spiritual support. A leader or member of your place of worship may provide guidance and care for you and your loved ones.



# Managing the Cost of Your Care

Treating ovarian cancer can be expensive. The costs can be a burden for some people and may affect medical decisions. Ask about costs and talk openly about them before, during, and after treatment. Since it can be hard to understand the details of insurance policies (whether they are from a private company or the government), ask for help if you need it.



Your health care team may be able to suggest ways to help reduce or manage medical costs, or direct you to support services geared for people who are fighting cancer. For more information about managing costs, go to www.cancer.net/managingcostofcare.





# Concluding Thoughts

By reading this booklet and watching the video, you've taken some positive steps in coping with ovarian cancer. You've learned that there are many ways to treat ovarian cancer and to improve your overall health and wellness.

Having ovarian cancer can be a time of personal challenge.

Cancer, and cancer treatments, are never easy. Yet you may also find that during this time you have a renewed desire to make the most of each day. No two people—and no two cancers—are exactly alike. But you can use the information in this booklet to begin charting your own course.

By working with your health care team and your personal support network, you can give yourself the best chance of staying healthy and getting the most from whatever treatments you choose.

# RESOURCES



# Credits

**American Cancer Society** 

www.cancer.org

CancerCare, Inc. www.Cancercare.org

Cancer.Net

Cancer Support Community

www.cancersupportcommunity.org

**Centers for Disease Control and Prevention (CDC)** www.cdc.gov

ClinicalTrials.gov (NIH) www.clinicaltrials.gov

**Coalition of Cancer Cooperative Groups** 

www.cancertrialshelp.org

**National Cancer Institute** 

www.cancer.gov

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

www.sharecancersupport.org

Society of Gynecologic Oncology

www.sgo.org

**Young Survival Coalition** 

www.youngsurvival.org

*Understanding Ovarian Cancer* was made possible through the expertise, funding, time, and efforts of many contributors.

#### PRESENTER

#### Society of Gynecologic Oncology

The Society of Gynecologic Oncology (SGO) is the premier medical specialty society for health care professionals trained in the comprehensive management of gynecologic cancers. The SGO contributes to the advancement of women's cancer care by encouraging research, providing education, raising standards of practice, advocating for patients and members, and collaborating with other domestic and international organizations.

SGO members provide multidisciplinary cancer treatment including chemotherapy, radiation therapy, surgery and supportive care. They practice in a variety of settings, including academic institutions and hospitals, major regional cancer centers and private practice. Visit www.sgo.org for more information.



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