

Ovarian Cancer in Black and African American Communities

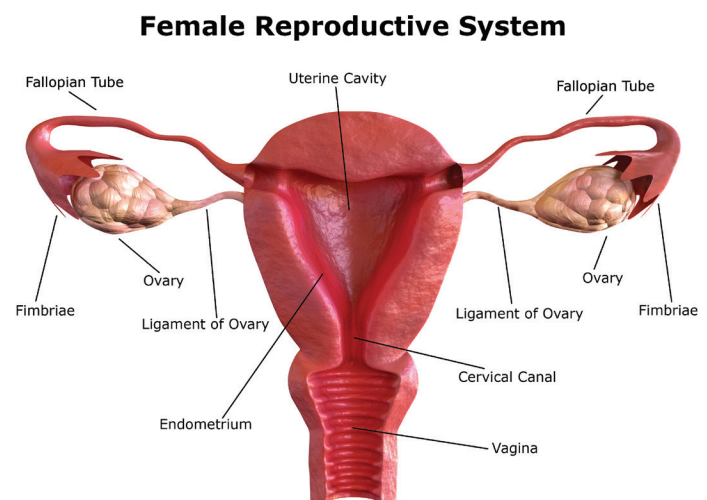
This fact sheet is for people living with ovarian cancer and their families. It is also for anyone concerned about the impact of this disease on Black and African American persons. By learning more, people with this cancer can live longer, healthier lives and help inform others.

WHAT IS OVARIAN CANCER?

Ovarian cancer is one of the top 5 causes of cancer-related deaths in the U.S. among people assigned female gender at birth. Ovarian cancer primarily develops after the age of 40. While ovarian cancer is more commonly diagnosed among white people, Black and African American persons are more likely to be diagnosed at advanced stages of this disease. This can lead to poorer treatment outcomes and lower rates of survival.



When a cell begins to grow out of control, it can develop into cancer. Cancer cells may spread to other parts of the body (metastasis). Ovarian cancer can develop in the cells of the ovaries or fallopian tubes. The ovaries and fallopian tubes are part of the female reproductive system. There is usually one ovary and one fallopian tube on each side of the uterus.



Ovarian cancer is a broad term. It includes epithelial ovarian, fallopian tube, and peritoneal cancers.

To learn more about ovarian cancer visit www.CancerSupportCommunity.org/Ovarian-Cancer

OVARIAN CANCER RISK FACTORS

Risk factors are things that can increase the chance of developing a disease. Certain cancer risk factors can be changed. Others, like a person's genetic history or age, cannot be changed. Some known risk factors that can increase the risk of developing ovarian cancer include:

- Being over the age of 40
- Being overweight or having obesity
- Having a history of endometriosis
- Having children later in life or never having children
- Having a personal or family history of ovarian, breast, or colorectal cancer
- Having certain genetic mutations, such as:
 - BRCA1 or BRCA2 genes
 - Hereditary Non-Polyposis Colon Cancer (HNPCC) or Lynch syndrome
 - And others

WHAT CAN HELP REDUCE THE RISK?

It is unclear exactly why ovarian cancer outcomes differ for Black or African American persons. So, it is important to talk to loved ones about the ways they can reduce their risk of developing this cancer. Let your family know who has had cancer, what kind, and how old they were when they had it. If you have genetic testing, share the results even if they are negative. This information can help family members take steps for their health. The more people talk about ovarian cancer, the more can be learned to reduce its toll on families and the community.

Other helpful steps to reduce the risk include:

- Knowing the factors that may increase the risk of developing ovarian cancer. Once you are aware of these factors, make any lifestyle changes that will improve your overall health. This could mean getting more exercise or avoiding smoking. Talk about these factors with your family and loved ones.
- Asking a physician about oral contraceptives. Taking oral contraceptives (birth control pills) can help reduce the risk of developing ovarian cancer.
- Attending any routine medical appointments. Early diagnosis helps. The earlier a person is diagnosed, the more options will be available for treatment and overall cancer care.



KNOW YOUR HISTORY AND GET TESTED: GENETIC TESTING AND BIOMARKER TESTING

If you or a loved one has been diagnosed with ovarian cancer, talk with your family. Sharing your family history with cancer and other diseases can help everyone prepare. Everyone can take action to better their health. Ask about testing. Two kinds of tests can provide more information about ovarian cancer:

Genetic testing looks for mutations or changes in your genes. Ovarian cancer can run in Black and African American families through the BRCA (breast cancer) genes. It can also be caused by genes linked to Lynch syndrome. If you have ovarian cancer, ask for genetic testing. This is especially important if you have a family history of breast or ovarian cancer. If you test positive for BRCA or another cancer gene, talk with the genetic counselor about the next steps – for you and for your family members.

Biomarker testing looks for biomarkers in your cancer sample. Biomarkers tell your doctor about the subtype of the cancer in your body. The test results can be used to help guide your treatment options. BRCA, HRD, LOH, and MSI-High, TMB or dMMR are biomarkers linked to ovarian cancer. Even if you are not born with a BRCA mutation, your cancer cells may develop one. Knowing if you inherited a BRCA mutation or if your tumor developed one can help your doctor decide which treatments are best for you.

SIGNS & SYMPTOMS

It is important to be aware of the subtle symptoms of ovarian cancer that often get missed. The most common symptoms include:

- Fatigue
- Bloating or unexplained fullness
- Pelvic or abdominal pain
- Difficulty eating or feeling full quickly
- Increased urination or urge to urinate
- Pain or bleeding during sexual intercourse

If you experience ongoing symptoms that are new or unusual, talk with your doctor to make sure your concerns are addressed.

TREATMENT OPTIONS

Ovarian cancer is usually treated with surgery and chemotherapy. During surgery, a gynecologic oncologist will remove as much of your cancer as possible. If the cancer has spread, other organs may also need to be removed.

Chemotherapy (also called chemo) uses drugs to destroy or damage fast-growing cells like cancer cells. Your doctor may recommend chemotherapy before surgery (neoadjuvant). This can help reduce the size of the tumors, so they are easier to remove.



CONSIDER CLINICAL TRIALS

Clinical trials find new and better ways to prevent or treat cancer. A clinical trial may be the only way to gain access to a promising new treatment option. There are clinical trials available for all stages of the ovarian cancer journey.

Sadly, not all people have always experienced the highest standards of cancer care. Black and African American persons have historically been mistreated or excluded from high quality health care in medical studies. The ethical abuses that took place are upsetting and should not be forgotten.

Today the U.S. Food and Drug Administration (FDA) oversees clinical trials to keep all patients safe. Researchers must have their study approved by a review board before enrolling participants. Anyone who takes part in a study must go through a process called informed consent. This formal process explains the goals of the trial, potential benefits, any risks or side effects, and alternatives to participating. This is a good time to ask questions. You can also ask questions throughout the trial. Joining a trial is always voluntary. You have the right to stop participating at any point.

A person's age, gender, and even race or ethnicity may affect how their cancer responds to treatment. Because of this it is important to increase the diversity of participants in clinical trials. When people of color participate in clinical trials, this

helps to ensure the best treatment options are made available to them. The clinical trial results can also better show how new treatments will work with all patients.

Talk to your doctor to learn more about what clinical trials may be available to you.

GETTING A SECOND OPINION

At any point in your care, you can ask for a second opinion. Another hospital or doctor may offer a different treatment, including clinical trials. They may have more useful support services or be a better fit for you in other ways.

Do not worry about hurt feelings.

You can always return to your first doctor if you want.

WHEN CANCER COMES BACK

Black and African American persons are more likely to have their ovarian cancer return. Sadly, doctors still do not understand why some cancers come back after initial treatment. After treatment, your doctor may review your CA-125 levels and order more scans to monitor your cancer. If your cancer returns, your doctor may determine if your cancer is platinum sensitive or resistant. This will help inform your next treatment options.

After you complete your chemotherapy treatment, your doctor may also recommend maintenance therapy. Maintenance therapy



is used to stop or slow your cancer's growth or to prevent it from coming back.

Sometimes cancer that returns is not the same cancer you had before. This is a good time to ask again about clinical trials. There may be new trials available. You may also be eligible for trials you were not eligible for before.

COST OF CARE

During cancer treatment, it is important to know the costs of your care and how you can maintain your sense of control. You may not only have bills from your treatment, but also transportation, childcare, and more.

You may find it helpful to work with a financial navigator or counselor. These professionals can help you estimate costs and look for financial assistance. The Cancer Support Helpline® can also help you navigate financial issues and provide resources to help manage the costs of cancer and its treatment. The trained Cancer Support Helpline staff can be reached toll-free at 888-793-9355.

To learn more about the financial side of cancer and where to go for help visit www.CancerSupportCommunity.org/Cost.

COPING WITH OVARIAN CANCER

Ovarian cancer can take a lot out of the person who has it and those who care for them. It requires physical and emotional energy, as well as time and money. You may

not be able to do all the things you used to do, at least for a while. It is important to take care of yourself. This may mean putting your needs above other people's. This may be hard to do if you are used to taking care of others. It may also mean advocating for yourself – when you are uncomfortable or in pain – to get the care you need to feel as well as possible.

It helps to have support. There are many places to turn to, including social workers, therapists, and spiritual/faith leaders. Ask your care team if they can recommend online or in-person support groups. It might take a couple of tries to find the right person or group. It can be helpful to connect with people going through similar situations. Seek out patient advocacy groups that work with people diagnosed with ovarian cancer. They can provide a variety of support and educational resources as well.



OVARIAN CANCER RESOURCES

The Clarity Foundation • 858-657-0282 • www.clarityfoundation.org

SHARE Cancer Support • 844-275-7427 • www.sharecancersupport.org

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

CANCER SUPPORT COMMUNITY RESOURCES

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-8pm ET and Sat 9am-5pm ET.

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.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

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

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

MyLifeLine — CSC's private, online community 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.

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.

This publication is available to download and print yourself at www.CancerSupportCommunity.org/Ovarian-Cancer.

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.

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Ovarian Cancer
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