

Talking About Ovarian Cancer

A Guide for Talking with Your Healthcare Team



This guide can help you self-advocate and have better discussions with your healthcare team after an ovarian cancer diagnosis. It has questions to ask your healthcare team and tips for talking about symptoms, treatment, and getting the support you need.

UNDERSTANDING OVARIAN CANCER

The ovaries, a component of the female reproductive system, are where ovarian cancer begins. The most common type, known as epithelial ovarian cancer, starts in the ovarian outer layer. Different kinds include stromal tumors, which grow in the tissue that holds the ovaries together and makes hormones, and germ cell tumors, which grow in the cells that make eggs. Many cases are not diagnosed until the cancer has spread because the early symptoms, such as bloating or pelvic discomfort, can be unclear.

After an ovarian cancer diagnosis, it's important to learn what type of cancer you have and what stage it's in. This information helps your care team plan the most effective treatment. Two important tests are often recommended at this point. First, a genetic test, done with a blood or saliva sample. This test should look at all genes linked to hereditary ovarian cancer not just BRCA1 and BRCA2. The second test, called a biomarker test, looks at a sample of your tumor to see if certain treatments may work better than others.

Biomarkers like BRCA1, BRCA2, HRD (homologous recombination deficiency), and MSI (microsatellite instability) can guide your treatment options, which may include surgery, chemotherapy, targeted therapy, or immunotherapy.



Before getting these tests, it's a good idea to check with your insurance provider to confirm coverage. To learn more about ovarian cancer, available tests, and support resources, visit

www.CancerSupportCommunity.org/Ovarian-Cancer.

TIPS FOR TAKING CONTROL



Engage with your healthcare team.

Write down your questions before each doctor's visit. Keep a journal to take notes during your visit. Use a binder to keep any labs, imaging reports, and other receipts in one place, unless you have a patient portal that does this for you. Repeat back what you hear for clarity and understanding.



When possible, take someone with you to appointments for support and an extra set of eyes and ears.

They can help you take notes during the appointment. If they cannot be there in person, consider trying a video call on your phone or computer. If you go alone, ask your doctor if it is OK to record your conversation.



Ask questions until you understand what is being said. If needed, ask to hear or read information in your preferred language. If you are a visual learner, you can ask your doctor to provide a picture or graphic to help.



Get familiar with your healthcare team and their roles. Know who to contact on your healthcare team with questions or concerns.



Talk to your healthcare team or financial navigator about ways to manage treatment costs.



Consider getting a second opinion. If your doctor is not a board-certified gynecologic oncologist, if possible, try to get a second opinion with a board-certified gynecologic oncologist. Do not worry about hurt feelings. You can get a second opinion at any point.

If possible, try to see a gynecologic oncologist at a high-volume academic or cancer center. These specialists are trained to treat ovarian cancer, and having an experienced surgeon can make a big difference in your care and outcome.



MAIN TYPES OF OVARIAN CANCER TREATMENT

Ovarian cancer treatment usually includes one or more of the following:

Surgery: Removing the cancer by taking out the ovaries and sometimes nearby tissues.

Chemotherapy: Using medicines to kill cancer cells, either through a vein or directly in the belly.

Targeted therapy: Medicines that focus on specific parts of cancer cells to stop their growth.

Radiation therapy: Using high-energy rays to kill cancer cells (used less often).

Immunotherapy: Helping your immune system fight the cancer (still being studied).

Your doctor will help decide the best treatment for you.

Below are some of the symptoms people with ovarian cancer may experience. Think about how often they may have affected you since your last visit. Talk to your healthcare team about how best to manage them.

	Rarely	Sometimes	All the time
Extreme fatigue, weakness, dizziness, shortness of breath, or falling			
Hot flashes, migraines, or other signs of menopause			
Difficulty thinking clearly or remembering (brain fog or chemo brain)			
Feeling worried, anxious, overwhelmed, depressed, or mood swings			
Nausea, diarrhea, and/or constipation			
Changes in taste/appetite			
Mouth pain/sores			
Weight loss or gain, swelling (lymphedema)			
Loss of sexual desire, problems with intimacy, and/or urinary problems			
Pain or nerve problems (neuropathy)			
Skin problems/rashes			
Others:			

How often are the above symptoms or side effects impacting the following areas?

	Rarely	Sometimes	All the time
Unable to go to work or school, do daily tasks, or take care of self or others			
Unable to do activities I usually enjoy, such as being active or traveling			
Low confidence or self-image			
Difficulty sleeping and/or insomnia			
Social relationships/feeling isolated			
Sexual relationships			
Eating and/or ability to exercise			
Others:			



THINK ABOUT YOUR TREATMENT & PERSONAL GOALS

When you talk to your doctor about your treatment options, ask about the goals of the treatment and consider if these align with your own personal goals for getting treatment. You can also choose NOT to treat your cancer. If you choose not to receive chemotherapy, you can still receive supportive care which focuses on managing the symptoms that come from advanced ovarian cancer.

POSSIBLE PERSONAL GOALS MAY BE TO:

- 1 Live as long as possible
- 2 Live as well as possible, even if this is a shorter life
- 3 Reach a certain milestone/special event

Let each member of your healthcare team know about your treatment and personal goals. Your goals may change over time, so allow yourself this freedom.



SETTING YOUR PERSONAL GOALS FOR TREATMENT

Here are some questions for you to consider and discuss with your doctor.

Physical, Emotional, & Sexual Health and Well-Being

- What does wellness look like to you?
- What do you want to be able to do physically, during or after treatment?
- What symptoms or side effects do you want to avoid or manage?
- How important is it to maintain your sexual health and intimacy?

Family & Social Relationships

- Are there people in your life that you want to spend more time with or support?
- Are there upcoming family milestones or events you want to be present for?

Work, School, & Home

- Do you want or need to continue working or attending school? What changes could help you balance treatment with your responsibilities?
- What kind of help do you need at home or with daily tasks?



Social Support & Community Involvement

- What would good support look like for you right now?
- Is staying involved in your community, advocacy, or support groups important?

Personal and Spiritual Growth

- What spiritual and wellness practices are important to you? Are there spiritual practices or beliefs that bring you comfort?
- What personal or emotional goals do you want to focus on?

Other

What else is important to you?

YOUR OVARIAN CANCER CARE TEAM

When you are diagnosed with ovarian cancer, you will likely be cared for by a team of specialists who each play an important role in your treatment and support. Here are some of the key members you may meet:

Gynecologic oncologist: A doctor who specializes in cancers of the female reproductive system. They usually perform surgery and often oversee your overall cancer treatment plan.

Medical oncologist: A doctor who specializes in treating cancer with medications like chemotherapy, targeted therapy, or immunotherapy.

Nurse navigator or oncology nurse: A nurse who guides you through the treatment process, coordinate appointments, answer questions, and provides emotional support.

Palliative care specialist: Will focus on relieving symptoms and improving quality of life at any stage of cancer, not just end-of-life care.



PREPARING FOR YOUR NEXT HEALTHCARE VISIT

Let your healthcare team know how you are feeling at each appointment and if you notice any changes. It can be helpful to write down any questions or concerns before each doctor's visit. Below are some suggested questions and discussion points. Focus on the issues that are most important to you.

At diagnosis or when getting a second opinion:

Has genetic testing been ordered for me? Has biomarker testing been ordered for me?

Can you explain my test results to me? Are there any other tests I should have right now?

What type of ovarian cancer do I have? What is the cancer's stage?

What are my treatment options?

What is the goal of each treatment? Is my cancer still curable?

What side effects might I expect, and how best can I manage them?

What side effects are considered an emergency?

During treatment:

The symptoms and side effects that are impacting me the most are:
[Fill in your answers from Page 3.]

They are interfering with my life in the following ways:
[Fill in your answers from Page 4.]

What can we do to manage these symptoms?

Could complementary therapies or supportive/palliative care help manage my symptoms and side effects? Can you refer me to a palliative care specialist?

WHAT IS PALLIATIVE CARE?

Palliative care is a type of supportive care that helps you manage the symptoms of cancer as well as the side effects of treatment. It aims to help patients, and their caregivers or care partners, maintain their best possible quality of life. Palliative care addresses physical, social, emotional, and spiritual concerns during treatment. The palliative care team anticipates and helps manage difficult symptoms, pain, and side effects.

To learn more, read CSC's **Understanding Supportive Care** resource by visiting www.CancerSupportCommunity.org/sites/default/files/fsac/Understanding_Supportive_Care.pdf

GENERAL QUESTIONS TO ASK AT ANY TIME & DISCUSSION POINTS

My treatment goals are: (See the bottom of Page 1 for reference.)

Is my current treatment the best option for me to meet these goals?

What other treatments are available to me? Are there any new treatments or clinical trials that may be right for me?

Do I need additional biomarker testing?

Should my tumor be tested for HER2/neu or folate receptor alpha (FR α) biomarkers?

Are there treatments or drugs that work just as well but would cost me less?

How can I manage treatment costs? Is there a financial navigator whom I can talk with?

What is the best way to get in touch with you during office hours? What about after hours and on weekends?



FINANCIAL SUPPORT

Even with a healthcare plan or private insurance, treatment can be expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.

- Talk with your healthcare team and pharmacist about the cost of your treatment.
- Ask your doctor to refer you to an oncology social worker, financial counselor, or to a nonprofit organization for help managing financial issues and costs.
- Reach out to your healthcare plan or insurance to find out what resources they have that could help you.
- Ask about pharmaceutical assistance programs and what the qualification requirements are.
- If your treatment center is far away, ask if there are assistance programs that can help cover your travel costs.

To learn more about ways to manage the cost of treatment, visit:

www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment.



GETTING SUPPORT

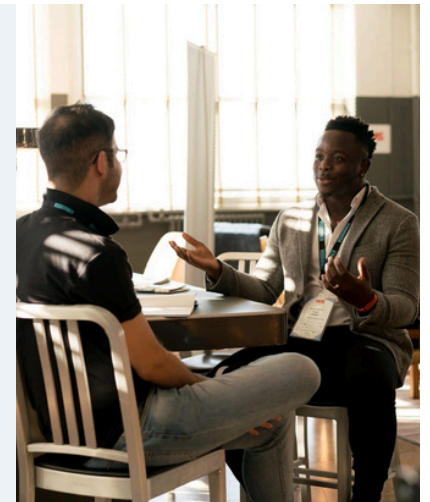
Think about people in your life who can help (your spouse or partner, friends, faith community, support group, or co-workers).



Make a list of things you need help with (childcare, meal prep, laundry, etc.) and who can help with each task. Consider using CSC's **MyLifeLine.org** to help you stay organized and let friends know what you need.

Ask your healthcare team about resources for social, emotional, and practical support. You can also ask for a mentor or to be matched with another person with ovarian cancer.

Turn to the back page of this guide to see a list of trusted organizations. CSC and many other organizations have helplines, support groups, online discussion boards, and more ways to seek support from others who have cancer.



FINANCIAL RESOURCES

CancerCare

800-813-4673 | www.CancerCare.org/Financial

Cancer Financial Assistance Coalition

www.cancerfac.org

Patient Advocate Foundation

800-532-5274 | www.PatientAdvocate.org

OVARIAN CANCER RESOURCES

Cancer Support Community

888-793-9355 | www.CancerSupportCommunity.org/Ovarian-Cancer

Ovarian Cancer Research Alliance

212-268-1002 | www.ORCAHope.org

American Cancer Society

800-227-2345 | www.Cancer.org/Cancer/Ovarian-Cancer

Facing Our Risk of Cancer Empowered (FORCE)

866-288-7475 | www.FacingOurRisk.org

Livestrong Fertility

855-844-7777 | www.Livestrong.org/We-Can-Help/Livestrong-Fertility

SHARE

844-275-7427 | www.ShareCancerSupport.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-Thurs 11am-8pm ET and Fri 11am-6pm 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 over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more
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 secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now 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**.

For print copies of this publication or other information about coping with cancer, visit **Orders.CancerSupportCommunity.org**.

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