# Preparing for Your Doctor's Visit



### A WORKSHEET FOR PEOPLE WITH OVARIAN CANCER

If you have **ovarian cancer**, complete this worksheet to help you talk with your health care team about symptoms, treatment options, side effects, and getting the emotional and practical support you need.

### **TIPS FOR TAKING CONTROL**

- Know what kind of ovarian cancer you have and what stage it is.
- Two types of tests can help you and your doctor choose the best treatment and suggest clinical trials that are right for you. Before testing, contact your insurer to be sure that they cover these tests. For more on testing, go to www.CancerSupportCommunity.org/Ovarian-Cancer.
  - A genetic test of your blood or saliva can tell if your ovarian cancer is the type that is inherited. Your genetic
    test should look for all the genes linked to hereditary ovarian cancer and not just BRCA1 and BRCA2.
  - A sample of your tumor can be tested to see if some treatments might be more effective than others. Your
    doctor tests your tumor for biomarkers such as BRCA1, BRCA2, HRD, and MSI-High.
- Be an active part of your health care team. Write down your questions before each doctor's visit. Keep a journal to take notes during your visit. Use a binder to include all 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.
- 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 your loved one can't be there in person, consider trying a video call on your phone or computer. If you go alone, ask your doctor if you can use a recorder or cell phone to record your conversation.
- Ask questions until you understand what is being said. Ask to hear or read information in your first language. You can ask your doctor to draw you a picture or compare it to something you already know.
- Know who on your health care team to contact with questions or problems and who to contact after hours.
- Talk to your health care team or financial navigator about ways to manage treatment costs.
- Consider getting a second opinion. You can get a second opinion at any point.

Below are some of the things people with Ovarian Cancer may experience. Think about how often they have affected you since your last visit. Talk to your health care team about how best to manage them.	Rarely	Sometimes	All the Time
Extreme fatigue, weakness, dizziness, shortness of breath, or falling			
Hot flashes, migraines, and other menopausal symptoms			
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 or 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) or skin problems/rashes			
Others:			

How often are cancer or side effects interfering with your life?	Rarely	Sometimes	All the Time
Unable to go to work/school, do daily tasks, or take care of self or others			
Unable to do activities I normally enjoy, such as being active or traveling			
Confidence/self-image/clothes don't fit			
Difficulty sleeping/insomnia			
Social relationship/feeling isolated			
Sexual relationships			
Eating and/or 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 how each treatment might affect the goals that you have for your life. If you choose not to receive treatment, think about your goals for the care that you receive. Possible goals may be to live as long and/or as well as possible, or make it to a special event/milestone. Let your health care team know about your treatment and personal goals.

Physical, Emotional, & Sexual Health and Well-Being	What is most important for you to be able to do?
Family and Social Relationships	What's going on in the lives of others that is important to you?
Work/School/Home	Do you want or need to continue working? Can you adjust your schedule, responsibilities, or career goals? Are you getting the help you need for tasks at home?
Community/ Involvement	Are you getting the support you need from your community? Are you able to stay active/involved in your community?
Personal and Spiritual Growth	Are you taking care of yourself spiritually and emotionally?
Other	What else is important to you?

#### PREPARING FOR YOUR NEXT HEALTH CARE VISIT

If you are feeling either better or worse today than at your last appointment, let your health care team know what has changed. Write down your concerns before each doctor's visit. Below are some suggested questions. Concentrate on the issues that are most important to you.

#### At Diagnosis/Progression/When Getting a Second Opinion

- What type of Ovarian Cancer do I have? What stage?
- Can you explain my test results to me? Are there any other tests I should be having right now?
- What is the goal of this treatment? What side effects might I expect, and how can I prepare for them?
- What side effects should I let you know about?

#### **During Treatment**

- The symptoms and side effects that are affecting me the most are: [Fill in your answers from Page 1].
- These are interfering in my life in the following ways [Fill in your answers from the top of Page 2].
- 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?

#### **General Questions to Ask Any Time**

- My top goals for treatment are: [Fill in your answers from the bottom of Page 2.]
- Is the treatment that I am currently on the best treatment 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 any additional testing?
- Are there treatments or drugs that work as well but would cost me less?
- How can I manage treatment costs? Is there a financial navigator that I can talk with?
- What's the best way to get in touch with you during office hours and after hours/on weekends?

#### **GETTING SUPPORT**

Think about people in your life who can help. It might be your spouse or partner, adult children, friends, faith community, support group, or coworkers. You or a caregiver can make a list of the ways each of them can help (childcare, meal prep, housework, transportation, laundry, etc.). Consider using **MyLifeLine.org** to let friends know what you need and help you stay organized. Ask your health care team about resources for getting the support you need.

Use trusted websites when searching for information online (see back page). Turn to the back page for trusted organizations. CSC and these organizations have helplines, online discussion boards, support groups, peer matching services, and more ways to seek support from others who have ovarian cancer.

#### **FINANCIAL RESOURCES**

Even with health insurance, treatment is expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.

Talk with your health care team and your pharmacist about the cost of your treatment. Ask your doctor to refer you to an oncology social worker, patient navigator, financial counselor, or nonprofit organization for help managing the financial issues and costs. Ask if there are prescription assistance programs that can help cover all or part of the cost of your medications.

The more you know about your specific treatment plan, the more you can help to reduce unexpected costs. To learn more about ways to manage the cost of treatment, visit: www.CancerSupportCommunity.org/cost.

# Financial Support Resources

Cancer Support Community • 888-793-9355 • www.CancerSupportCommunity.org/Cost CancerCare • 800-813-4673 • www.cancercare.org/financial Cancer Financial Assistance Coalition • www.cancerfac.org Patient Advocate Foundation • 800-532-5274 • www.patientadvocate.org

# Other Ovarian Cancer Information & Support

American Cancer Society • 800-227-2345 • www.cancer.org/cancer/ovarian-cancer 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/we-can-help/livestrong-fertility Ovarian Cancer Research Alliance • 212-268-1002 • www.ocrahope.org SHARE • 844-275-7427 • www.sharecancersupport.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®** — Whether you are newly diagnosed with cancer, a long-time cancer survivor, caring for someone with cancer, or a health care professional looking for resources, CSC's toll-free Cancer Support Helpline (888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you Mon – Fri, 9 am – 9 pm ET.

**Open to Options**<sup>®</sup> — If you are facing a cancer treatment decision, this research-proven program can help you. In less than an hour, our trained specialists can help you create a written list of specific questions about your concerns for your doctor. Appointments can be made by calling 888-793-9355, visiting **www.CancerSupportCommunity.org**, or by contacting your local CSC or Gilda's Club providing this service.

Services at Local CSCs and Gilda's Clubs — Almost 50 locations plus 120 satellite locations around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost to the member.

**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** — CSC's Cancer Policy Institute provides updates on policy issues that impact the health and well-being of cancer patients and survivors. Join the Network to make your voices heard with federal and state policy makers. www.CancerSupportCommunity.org/join-our-movement.

**Cancer Experience Registry**<sup>®</sup> — The Registry is a community of people touched by cancer. The primary focus of the Registry is on collecting, analyzing, and sharing information about the experience and needs of patients and their families. To join, go to www.CancerExperienceRegistry.org.

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For more information and resources, please visit the CSC Ovarian Cancer page at www.CancerSupportCommunity.org/ovarian-cancer.

Share your experience and make your voice heard. Join the Cancer Experience Registry and participate in the special community of people facing ovarian cancer at www.CancerExperienceRegistry.org.

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