

Talking About Cervical Cancer

A guide for talking about your diagnosis and treatment with your cancer care team

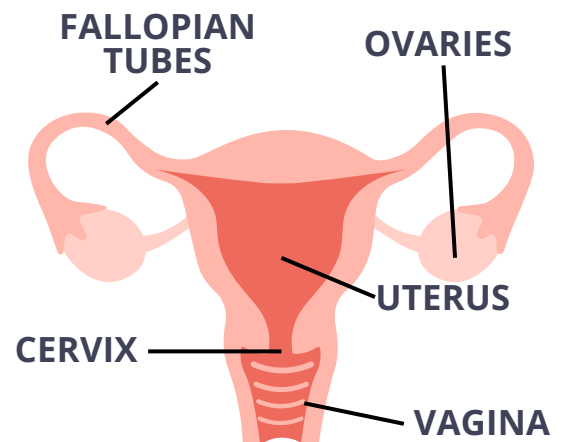


Being diagnosed with cervical cancer can be overwhelming. This guide can help you take control and have more confident and informed discussions with your healthcare team after a diagnosis.

Inside, you'll find:

- A clear overview of cervical cancer and your treatment options
- Key questions to ask your doctors and care team
- A worksheet to help you identify your goals and priorities
- Reliable resources for information and support

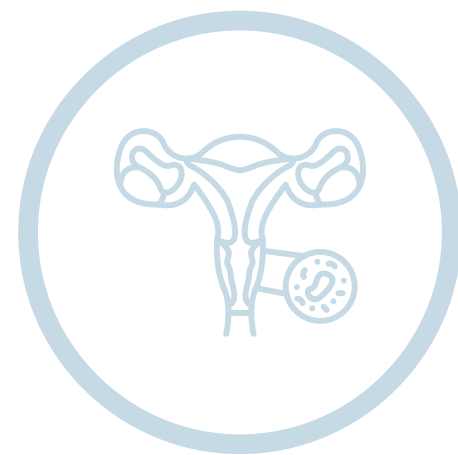
Use this guide to get the answers you need and make decisions that feel right for you.



WHAT IS CERVICAL CANCER?

Cervical cancer forms in the tissues of the cervix, which is the lower part of the uterus that connects to the vagina.

Regular preventive screening, such as Pap tests, human papillomavirus (HPV) tests, including HPV self-collection (a vaginal swab you can do yourself in a private setting), can detect cervical dysplasia (pre-cancer) or cervical cancer early. Cervical cancer is most treatable when it is found early. Infection with HPV is the most common cause of cervical cancer, accounting for over 95% of cases. HPV is the name for a group of more than 100 related viruses. Most cervical cancers and other HPV-associated cancers can be prevented with the HPV vaccine.



To learn more about cervical cancer, visit www.CancerSupportCommunity.org/Cervical-Cancer.

TIPS FOR TAKING CONTROL



Write down your questions before each doctor's visit.

Bring a notebook to take notes or use this resource guide to track your progress over time.



Bring someone with you to appointments, for support and an extra set of eyes and ears. If you attend alone, take notes or ask if you can record the conversation — always check with your doctor first to make sure recording is permitted.



Ask your doctor to explain anything you don't understand

when they are talking about your cancer. Your doctor should be able to find other ways to help you better understand your cancer and treatment options. Ask if they can provide any printed material to help you and your caregiver(s) understand. You can contact your healthcare team at any time if you want more information or clarity.



Be proactive about costs. Before starting treatment, take a moment to discuss financial concerns with your care team or financial navigator. You can explore options to manage costs, understand what to expect, and find resources that can help ease the financial burden, so you can focus on what matters most — your care and recovery.



Everyone's cancer experience looks different. Doctors will use different scans and tests to diagnose cervical cancer. These tests can also help see if the cancer has spread to other parts of the body and plan treatment moving forward. If detected early, cervical cancer can be easier to treat.



QUESTIONS TO ASK ABOUT YOUR DIAGNOSIS

What is the cancer stage?

Where is the cancer located?

Has the cancer spread? Is the cancer considered "advanced"?

What are the different options for treatment?

Does the cancer have a high chance of returning?

WORKING WITH YOUR CARE TEAM

Cancer treatment is complicated. It is always changing as new discoveries are made. You deserve a healthcare team you trust to provide you with the best possible care. Your team can include doctors, nurses, social workers, and other healthcare experts who work together. This is often called "multidisciplinary care."

Being able to trust your care team and talk openly about your treatment is important. You might have many options for your treatment, so let them know what matters to you. Ask questions, share your worries, and speak up if something does not feel right. You should feel heard and supported during your cancer experience.

GETTING A SECOND OPINION

If you feel that your doctor is not addressing your needs or concerns, consider talking with another doctor. Getting a second opinion allows you to learn whether another medical team agrees with the diagnosis and treatment plan. Other care teams or centers may have other treatment options available to you. They may also offer other supportive care options that are important to you. **Do not worry about hurt feelings.** It is important that you feel comfortable with your treatment team and plan. But remember, timely cancer treatment is key when deciding to seek multiple opinions.

TREATMENT FOR CERVICAL CANCER

Treatment for cervical cancer depends on:

- The stage of cancer you have
- How fast it is growing
- Your general health
- Your personal goals and preferences
- Your desire to preserve fertility



Below are treatment options your healthcare team may suggest:

Surgery: A surgeon removes any nearby tissues in the body that have cancer cells, which usually involves a hysterectomy (a surgery that removes the uterus and cervix) and removal of lymph nodes. Surgery may be used to treat Stage I tumors.

Radiation therapy: Radiation therapy is the use of high-energy rays to kill or damage cancer cells. Radiation treatments are commonly used for cervical cancer patients both in early stage and advanced stage disease, as it is highly effective. Early-stage cervical cancer can be treated with radiation with or without surgery, and radiation is also used where surgery is not an option. You may receive external radiation from a large machine aimed at the pelvis. This may be combined with internal radiation, called brachytherapy, where a thin tube is placed inside the vagina to deliver the treatment.

Chemotherapy: Chemotherapy (chemo) uses drugs to destroy or damage fast-growing cells like cancer cells. Chemotherapy for cervical cancer is usually given through a vein. It is sometimes combined with radiation therapy.

Targeted therapy: Targeted therapy uses drugs to target specific changes in cancer cells that help them to grow, divide, and spread. Targeted therapy drugs are designed to be more precise. They fight cancer cells while causing less harm to other cells in the body. There are different types of targeted therapies to treat cervical cancer.

Immunotherapy: Immunotherapy works with the body's immune system to find, attack, and kill cancer cells. These drugs can work in different ways. Some boost the immune system, so it can fight cancer better. Other immunotherapy drugs help the immune system better recognize cancer cells.



WHAT ARE CLINICAL TRIALS?

Consider talking to your healthcare team about clinical trials. Clinical trials are research studies. A clinical trial may be part of your treatment plan at any time — it is not a last resort option. They help us learn new and better ways to treat cancer. A clinical trial may be the only way to gain access to a promising new treatment option.

For more information about clinical trials, visit www.CancerSupportCommunity.org/Clinical-Trials.

KEEPING TRACK OF YOUR SIDE EFFECTS

It helps to learn more about the side effects of treatment before you begin. This way, you will know what to expect. When you know more, you can work with your care team to better manage any symptoms during and after treatment. Report any side effects to your care team as you experience them, so they can understand how your body responds to treatment and may offer options to provide relief.

Below are potential treatment side effects people with cervical cancer may experience. Think about how severe they are and how often they have affected you since your last doctor's visit, if at all. Talk to your healthcare team about how to best manage them.

	Rarely	Sometimes	Often
Fatigue (feeling very tired) or weakness			
Pain (general or in specific area)			
Hot flashes, migraines, or other signs of menopause			
GI issues (nausea, decreased appetite, diarrhea, constipation, urgency, discomfort)			
Loss of sexual desire, problems with intimacy, and/or urinary problems			
Changes in taste or appetite, mouth pain/sores, dehydration			
Weight loss or gain, loss of muscle mass, swelling (lymphedema)			

	Rarely	Sometimes	Often
Difficulty thinking clearly or remembering (brain fog or “chemo brain”)			
Mood changes (feeling worried, anxious, overwhelmed, depressed)			
Other side effects not listed here:			

There are resources that can help. Visit www.CancerSupportCommunity.org/Cancer-Treatment-Side-Effects for more information on how to manage the side effects of treatment.

PALLIATIVE CARE

Palliative care is a type of support that helps you feel better during or after cancer treatment. It focuses on relieving symptoms, like pain or fatigue. A palliative care specialist can help you manage any side effects and feel more comfortable.

Palliative care is different from hospice care. It is available at any point in the cancer experience. It can be available as early as the time of diagnosis. Palliative care is available for people with any stage of cancer. You can receive it at the same time as your cancer treatment. The goal of palliative care is to help you live as well as possible throughout your cancer experience.

To learn more about palliative care and other supportive care options, check out CSC’s resource, www.CancerSupportCommunity.org/Treatment-Options-Cancer.





THINK ABOUT YOUR TREATMENT AND PERSONAL GOALS

When you talk to your doctor about your treatment options, ask how each one might impact your personal life and goals. If you choose not to receive treatment, think about what kind of care will help you feel comfortable and meet your goals.

Some personal goals may be to:

- Be there for a special event/milestone
- Live as long and as well as you can
- Become an advocate and help others by sharing your experience
- Take part in research

Tell all the members of your care team about your treatment choices and personal goals. Your goals may change over time, and that is OK. Let your care team know if changes happen, so that they can support you in the best way possible.

SETTING YOUR PERSONAL GOALS FOR TREATMENT

Here are some questions for you to consider and discuss with your doctor, as you think about your personal and treatment goals. You may also find it helpful to discuss your goals with your family and loved ones first.

Physical, Emotional, & Sexual Health and Well-Being

- What is most important for you to be able to do and feel?
- 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 fertility and sexual health?
- What does feeling “emotionally well” look like for you?

Family and Social Relationships

- What is going on in the lives of others that are important to you?
- 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?
- How can you maintain meaningful relationships during treatment?
- Who do you want to make medical decisions for yourself if you are unable?

Work/School/Home

- Do you want or need to continue working or attending school? What kind of support or changes will help you with this?
- 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

- Are you getting the support you need from friends, family, or community?
- What would good support look like for you right now?
- Is getting or staying involved in your community, advocacy, or support groups important?

Personal and Spiritual Growth

- Are you taking care of yourself spiritually and emotionally?
- What spiritual and wellness practices are important to you? Are there spiritual practices or beliefs that bring you comfort?
- What helps you feel connected to something bigger than yourself?
- What personal or emotional goals do you want to focus on?

Other

- What else is important to you?





QUESTIONS TO ASK YOUR DOCTOR ABOUT TREATMENT & YOUR GOALS

What are my treatment options?

What are the benefits and risks of each treatment option that is available for me? What side effects should I watch out for during, immediately after, and long-term after treatment?

Are there other treatments options that work just as well but would cost less money?

Are there clinical trials that could help me?

Will my ability to have sex or have children change during treatment?

The symptoms and side effects that are bothering me the most are (see answers from above):

- These side effects are affecting my daily life in these ways:
- What can we do to manage these side effects?

My top goals for treatment are (see answers from above):

Can I keep working or attending school during treatment?

What can I do to stay active and feel better?

Is there a support group or social worker I can talk to about my experiences?

Who can I talk to if I am feeling overwhelmed or depressed?

FINANCIAL SUPPORT

Even if you have a healthcare plan, cancer treatment and other related costs during your experience can be expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.



Talk with your care team and pharmacist about how much your treatment will cost.



Ask your doctor to refer you to an oncology social worker, financial navigator, or 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.



Find out if there are programs from drug companies that can help pay for your medicines and ask what you need to qualify.



If your treatment center is far from home, 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, neighbors, 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 visiting www.MyLifeLine.org to help you stay organized and let friends know what you need.
- Ask your care team about resources for social, emotional, and practical support. You can also ask for a mentor or ask to connect with another person with cervical cancer.
- If you search for information online, make sure that you are using trusted websites.

Review the end of this guide to see a list of trusted organizations. Cancer Support Community and many other organizations have helplines, support groups, online discussion boards, and more ways to seek support from others who have cancer.

RESOURCES

CERVICAL CANCER RESOURCES

Cancer Support Community

888-793-9355 · www.CancerSupportCommunity.org/Cervical-Cancer

Cervivor, Inc

www.Cervivor.org

American Cancer Society

www.Cancer.org/Cancer/Risk-Prevention/HPV/HPV-Vaccine.html

Foundation for Women's Cancer

www.FoundationForWomensCancer.org

SHARE Cancer Support

844-275-7427 · www.ShareCancerSupport.org

National Cancer Institute (NCI)

800-422-6237 · www.Cancer.gov/Types/Cervical

NCI's Clinical Trials Registry

800-422-6237 · www.Cancer.gov/ClinicalTrials



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/Cervical-Cancer**.

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

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