

Talking About Endometrial Cancer



A Discussion Guide for Talking With Your Healthcare Team



Receiving a diagnosis of endometrial cancer can bring on many emotions. You may face a flood of information, decisions, and emotions. This guide is designed to empower you to take an active role in your care by learning about your diagnosis and how to improve communication with your healthcare team.



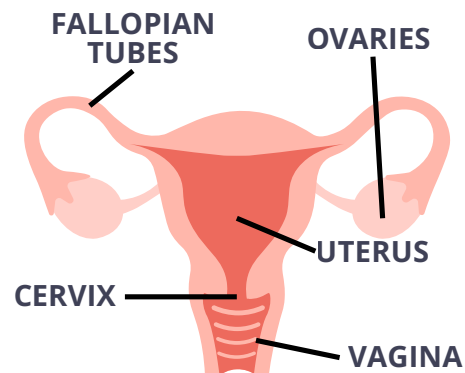
To learn more about endometrial cancer, visit
www.CancerSupportCommunity.org/Endometrial-Cancer



WHAT IS ENDOMETRIAL CANCER?

Endometrial cancer is cancer that forms in the tissue that lines the inside of the uterus, also known as the endometrium. Endometrial cancer is one type of uterine cancer. Uterine cancer can also start in the cells that make up the lining of the uterus.

When people say uterine cancer, they may often be referring to endometrial cancer.



With early testing, endometrial cancer can be found and cured at an early stage. Look for signs like irregular or heavy bleeding, pain, or bleeding after menopause. It is important to know that these symptoms can be due to conditions other than cancer. Make sure to talk with your primary care provider or gynecologist about any new or changing symptoms. They may have you complete additional tests or imaging to determine the cause. This may include:

PELVIC EXAM

The doctor feels the pelvic area. They check the vagina, uterus, bladder, and rectum for lumps or changes in shape and size. They may insert a speculum into the vagina to see the upper part of the vagina and the cervix.

TRANSVAGINAL ULTRASOUND

Sound waves and a computer are used to create a picture of the uterus. The picture can show tumors and abnormalities. If the endometrium (inner layer of the uterus) looks too thick, the doctor will do a biopsy. Ultrasound is not diagnostic, meaning that it does not tell you if there are or are not cancer cells.

ENDOMETRIAL BIOPSY

The doctor removes samples of tissue from the lining of the uterus. This is usually done in the doctor's office, but in some cases, the patient may need a dilation and curettage (D & C). This is a same-day surgery that gently widens the cervix and carefully removes a small amount of tissue. A pathologist (a doctor who examines tissue, blood, and other body fluids) then checks the samples for cancer cells. This biopsy is the definitive way to diagnose endometrial cancer.

PAP TEST OR PAP SMEAR

This is used to detect cancer of the cervix. The doctor takes cells from the cervix and upper vagina. The cells are sent to a lab to be checked for abnormal cells. While it does not usually find uterine cancer, it may be used to rule out cervical cancer.

CT SCAN (COMPUTED TOMOGRAPHY SCAN)

Detailed pictures of areas inside the body are taken from different angles. A dye may be swallowed or injected into a vein to help the organs or tissues show up more clearly.

MRI (MAGNETIC RESONANCE IMAGING)

Radio waves and a strong magnet are used to get a detailed image. An MRI may be used to see how far cancer has grown into the uterus.



TREATMENT FOR ENDOMETRIAL CANCER

Treatment for endometrial cancer depends on the stage and where the cancer is found. It can also impact your fertility (your ability to become pregnant and have a baby). If you still hope to get pregnant, talk with your doctor about your options before you start treatment. This will affect your treatment plan.

Surgery – Surgery is often the primary approach for treating endometrial cancer. This operation will be done either laparoscopically (small cuts and long, thin tools) or robotically, when the surgeon recommends this as safe and appropriate. Often, the surgeon will make a cut in the abdomen or belly.

The surgery may include three components:

- **A total hysterectomy:** This is an operation in which the uterus and cervix are removed.
- **A bilateral salpingo-oophorectomy:** This is removal of the ovaries and fallopian tubes.
- **Removal of nearby lymph nodes to check for cancer spread.**

In treating endometrial cancer, it is important to consider the potential lasting effects of treatment. You may experience side effects for the rest of your life, both mentally and physically. Since this cancer is in the area of reproductive organs, be sure to talk with your healthcare team to understand the potential side effects of treatment. You may have challenges with menopause and your ability to become pregnant. If you wish to become pregnant at any point in the future, talk with your healthcare team about your options to preserve your fertility.



Radiation therapy – Radiation therapy is the use of high-energy rays to kill or damage cancer cells. Radiation may be used after surgery or as a primary treatment if surgery is not an appropriate option. Techniques include:

- **External beam radiation therapy (EBRT):** Targets cancer from outside the body.
- **Brachytherapy:** Delivers radiation internally near the tumor site. Radiation helps reduce recurrence risk (risk of the cancer coming back) and manage symptoms. This may also be referred to as “internal radiation therapy.” Tiny tubes containing a radioactive substance are inserted through the vagina and left in place for a few days. This treatment may involve a hospital stay. To protect visitors from radiation exposure, they may not be allowed to stay with their loved one.

Hormone therapy – Hormone therapy is the use of drugs that block hormones that drive cancer growth. It is used after or in place of surgery. Progesterone pills are a common hormone therapy for endometrial cancer. Other drugs may be an option, too. Blood tests may help identify cancers that are more likely to respond to hormone therapy. Hormone therapy is also used to preserve fertility.

Chemotherapy –

Chemotherapy involves the use of drugs to destroy cancer cells. It is a systemic (whole body) treatment. Most people with endometrial cancer receive chemotherapy after surgery, sometimes with radiation. It is given through a vein. Often, you will get a combination of two drugs.



Clinical trials –

Clinical trials provide people with cancer access to new therapies. They are research studies to test new treatments or learn how to use current treatments better. Today's standard drugs were once in clinical trials. Tomorrow's drugs are in them today.

Immunotherapy – Immunotherapy uses the body's natural defenses (the immune system) to find, attack, and kill cancer cells

Targeted therapy – Targeted therapy aims to more precisely attack cancer cells. These drugs target changes in the genes or proteins of cancer cells that help them grow, divide, and spread.



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 treatment options, visit www.CancerSupportCommunity.org/Treatment-Options-Cancer.

Open to Options® – If you are facing a cancer treatment decision, the Cancer Support Community's Open to Options® program can help you prepare a list of personalized questions to share with your doctor. Our Open to Options® specialists can help you create a written list of specific questions about your treatment plan for your doctor. Call 888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.



Be Your Own Advocate

As a person with endometrial cancer, you are an active member of the healthcare team. At any point in your care, feel free to bring up any questions or concerns with your doctor or other healthcare team members. Asking questions and sharing your opinions in the decision-making process will help you feel more in control. **Your input is important and should help direct your cancer care experience.**

If you feel that your concerns are not addressed or aren't sure if you are seeing the correct specialist, you have the right to advocate for yourself. It is important to advocate for yourself — even when you are uncomfortable or in pain — to make sure that you get the support you need. You know your body best. Seek out the care you need when you notice any new symptoms or side effects.

MANAGING SIDE EFFECTS

Below are some of the treatment side effects people with endometrial cancer may experience. Think about how often you experience each one. Share this with your care team during your next visit. They can talk with you about how to best manage them. For more information about how to manage treatment side effects, visit www.CancerSupportCommunity.org/Managing-Side-Effects.

PHYSICAL SIDE EFFECTS	Rarely	Sometimes	Often
Fatigue (feeling very tired)			
Hot flashes or other signs of menopause			
Pain or discomfort			
Urinary problems			
Intimacy problems			
Shortness of breath			
Weight loss or gain			
Swelling (lymphedema)			
Other:			

EMOTIONAL SIDE EFFECTS	Rarely	Sometimes	Often
Fear of disease progression or upcoming appointments			
Feeling sad or depressed			
Feeling nervous, anxious, or afraid			
Infertility-related concerns			
Experiencing stigma			
Intimacy concerns			
Other:			

For more information and ways to support for your mental health, visit www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns.





PREPARING FOR APPOINTMENTS

Preparing for your appointments can help ensure you get the most out of your time with your care team. Start by writing down any questions or concerns you have, including anything that needs clarification. This helps you stay focused and ensures important topics are not forgotten. Bringing a caregiver or loved one can provide emotional support and help with remembering details or asking additional questions. Do not hesitate to ask about clinical trials or supportive resources that may benefit both you and your support system. Also consider requesting permission to record the conversation. This can be a helpful way to revisit complex information later and share it accurately with others involved in your care.

Caring for someone with endometrial cancer can be both rewarding and challenging. Every caregiver experience is different. It is normal to feel overwhelmed, stressed, or even frustrated as you balance your own life with your loved one's needs. **You are not alone in feeling these emotions.** It is completely natural to feel overwhelmed, frustrated, and tired. During this time, you may want to do all you can to support your loved one. **Taking care of yourself is not selfish; it is essential.** Seek out the support that is helpful for you. This could be through a family member, friend, or professional, such as a licensed therapist or social worker. If you are looking for peer support, consider joining a support group for caregivers. Talk with your care team about the support options available for you. For more information on caregiving, visit www.CancerSupportCommunity.org/Caregivers.



ENDOMETRIAL CANCER HEALTHCARE TEAM

The members of your care team may vary at different points throughout your care. These members may include:

Medical oncologist or gynecologic oncologist – Diagnoses and treats cancer. They will offer cancer treatment options and referrals. A gynecologic oncologist is a medical oncologist that specializes in gynecologic cancers (endometrial, cervical, vaginal, and ovarian).

Radiation oncologist – Manages radiation treatments.

Surgical oncologist – Performs surgery to remove cancer tumors and cells.

Gynecologist or obstetrician-gynecologist (OB-GYN) – A doctor who specializes in the health of the female reproductive system. This includes organs like the uterus, ovaries, fallopian tubes, and breasts. They perform regular tests such as a Pap smear and address symptoms relating to menopause and a menstrual cycle.

Oncology social worker and therapist/counselor – Helps you and your caregiver find resources to cope with cancer and its treatment side effects. Social workers can help navigate costs and help with practical concerns. Social workers and therapists are trained mental health professionals who can help you address your emotions through individual or group therapy.

Nurse (RN), Nurse Practitioner (NP), or Physician Assistant (PA) – Administers treatments and other medicines. They can help you understand your cancer diagnosis and treatment. They can be a good source of information and support. NPs, PAs, and RNs may work with the oncologist and help answer questions about your diagnosis. These healthcare professionals may also be helpful to talk to about fertility preservation options.



Patient navigator – Helps you navigate your care experience from the time you are diagnosed through treatment. They can help you talk with your healthcare team, set up appointments, and help with home care needs.

Financial navigator – Helps you and your loved ones understand the cost of different treatments and how your insurance plan may help cover costs. They may also help find financial assistance programs or payment plans to help ease the burden of receiving treatment.



QUESTIONS TO ASK YOUR CARE TEAM

What type of endometrial cancer do I have?

Has the cancer spread outside the uterus?

What stage is my cancer, and what does that mean?

What are my treatment options?

What treatment do you recommend, and why? What should I consider in deciding the best treatment plan for me?

What side effects should I look out for once I start treatment? What type of help will I need from a caregiver during my treatment?

What long-term side effects are possible from my treatment? What kind of follow-up care will I need?

Will my treatment affect my sexual health or intimacy with my partner? What can we do to maintain intimacy?

Will treatment affect my fertility? How will my treatment impact my experience with menopause?

Are there any new treatments or clinical trials that might be appropriate for me?

What are my options for receiving biomarker testing?

Who can I reach out to for support? Are there support groups or counseling options that are available to me and my partner or caregiver?

What resources are available for my partner or caregiver?

What is the contact information for when I have questions? Does this contact person or phone number change after hours?

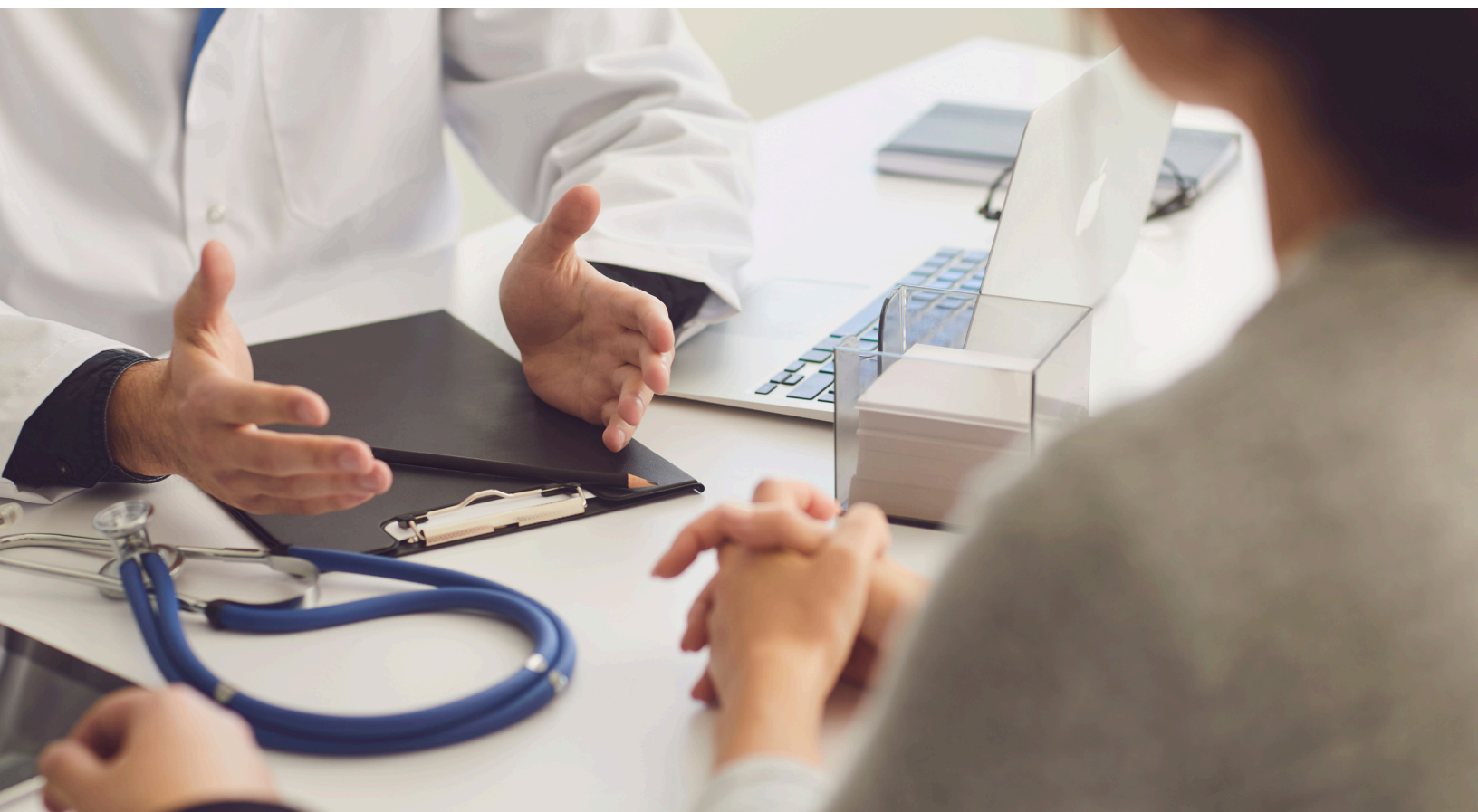
Is there a patient portal or phone application that would make communication easier?

How can I manage the costs of treatment?

Is there a financial navigator or social worker I can talk with about expenses or insurance questions?



Getting a Second Opinion – At any point in your care, you can ask for a second opinion. Many people may seek out a third opinion to confirm their diagnosis and review all available treatment options. Another hospital or doctor may offer different treatment, including clinical trials, or more useful support services. They may be a better fit for you in other ways, such as being closer to your home. Do not worry about hurting feelings. You can always return to the first doctor if you want. Remember, timely cancer treatment is key. You are entitled to decide what is best for you and your goals. Read more about seeking a second opinion at www.CancerSupportCommunity.org/Blog/Should-I-Get-Second-Opinion.



GETTING SUPPORT

It helps to have emotional support, both during and after cancer treatment. Talking with people who understand your experience can help you cope and feel in control. A good support system can also help you with practical things. Talk with your healthcare team about resources for social, emotional, and practical support. Ask if they can connect you to a support group for people with endometrial cancer. A social worker can be a great resource for mental health, financial, and transportation support. They may also connect you with other healthcare providers about managing side effects of treatment, such as how to cope with stigma and intimacy concerns. The back page of this resource includes 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 impacted by cancer.



Cancer Support Helpline® — If you need help finding resources or want help getting information about cancer, call Cancer Support Community's toll-free Cancer Support Helpline® at 888-793-9355. It is staffed by licensed community navigators and resource specialists who can assist you Monday - Thursday 11:00 a.m. - 8:00 p.m. ET and Friday 11:00 a.m. - 6:00 p.m. ET.



RESOURCES

ENDOMETRIAL CANCER RESOURCES

Cancer Support Community

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

Endometrial Cancer Action Network for African-Americans (ECANA)

www.ECANAWomen.org

Foundation for Women's Cancer

www.FoundationForWomensCancer.org

SHARE Cancer Support

www.ShareCancerSupport.org

NCI Clinical Trials

www.Cancer.gov/ClinicalTrials

ACS Endometrial Cancer

www.Cancer.org/Cancer/Types/Endometrial-Cancer.html



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/Endometrial-Cancer.

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

Frankly Speaking About Cancer:
Endometrial Cancer program partner:

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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 healthcare professionals to answer questions and learn more.

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