

SPOT THE SIGNS, SYMPTOMS, AND RISK FACTORS FOR ENDOMETRIAL CANCER (EC)

Too often, women with EC have reported that their symptoms were stigmatized and dismissed even though diagnoses and deaths from this type of uterine cancer are on the rise, and it remains under-recognized.

Use this brochure to learn more about symptoms and risk factors of EC, read patient stories, learn about the communities that have been heavily impacted, prepare for doctor visits, and much more.



ABOUT SPOT HER

Spot Her[®] is an initiative to help end the silence around endometrial cancer (EC) and empower all people across generations and cultures to speak up, take action, and spot the potential signs at an early stage—when EC may be more treatable.

Spot Her is brought to you by:













WHAT IS ENDOMETRIAL CANCER (EC)?

Found in the lining of the uterus, **EC accounts for 90%** of uterine cancer diagnoses. Uterine cancer is the 4th most frequently diagnosed cancer for women in the U.S. In 2023, it's estimated that there will be 66,200 new cases of uterine cancer, and it will result in 13,030 deaths.

Uterus

Cervia

Diagnoses and deaths from this type of cancer are on the rise across ethnicities—with greater increases in diagnosis rates seen across Native American/Alaska Native, Black, Asian/Pacific Islander and Hispanic communities.

EC occurs most commonly among women who have gone through menopause, but it can also occur much earlier. In fact, diagnoses are on the rise among younger women between the ages of 20 to 49, when fertility may be an important concern.

HOW CAN I SPOT THE SIGNS?

Some common signs of endometrial cancer (EC) may include:



Abnormal vaginal bleeding, spotting, or brownish discharge after menopause



Irregular or heavy bleeding in younger women before menopause



Pelvic pain or pressure

Symptoms common in later stages of EC can include feeling a mass and/or losing weight without trying. Less common symptoms include difficult or painful urination and/ or pain during intercourse. These are not all the symptoms of EC and they could be caused by other conditions. These symptoms could be easily overlooked, so it is important to talk to your doctor about any concerning symptoms as soon as they arise.

WHAT ARE THE RISK FACTORS

It's important to be aware of factors that may increase

the risk of developing endometrial cancer (EC) and talk to your doctor about any risk factors you may have.

Some common risk factors for EC include:

- Obesity
- Age (risk increases with age)
- 8

Personal history

- High-fat diet
- Lack of exercise
- History of testing positive for Lynch syndrome or another gene mutation linked to EC
- Type-2 diabetes
- Never having been pregnant
- Polycystic ovarian syndrome (PCOS) (risk could be almost 3 times higher for people living with PCOS)
- History of irregular periods
- Increased lifetime number of menstrual cycles
 - History of hormone therapy

Family history

- Family history of uterine cancer
- Family history of colorectal cancer linked to Lynch syndrome
 - Family history of a relative testing positive for Lynch syndrome or another gene mutation linked to EC



Reproductive history

FAMILY MEDICAL HISTORY MAY BE A RISK FACTOR

A family history of certain conditions may increase your risk of endometrial cancer (EC). **People in families with Lynch syndrome**, also known as hereditary nonpolyposis colon cancer (HNPCC), **have a higher risk of EC**.

Other genetic risk factors include (but are not limited to) mutations in the PTEN gene. People with an inherited PTEN mutation may have a condition called Cowden syndrome.



Actor portrayal

Genetic counseling can give you information about how genetic conditions might affect you or your family, and genetic testing **may help you to better understand if you might have an inherited risk** for EC. You should consult with your doctor about whether to receive genetic counseling and testing.

HEALTH DISPARITIES AMONG COMMUNITIES OF COLOR

Endometrial cancer (EC) **may be more treatable when detected at an early stage**. It's especially important for Black women to recognize the symptoms, as only 53% of Black women with the condition receive an earlystage diagnosis.

Studies have found that there are a **number of other factors** that contribute to increasing cases, deaths, and delayed diagnoses for Black women.

Among them are:

- Socioeconomic status
- Lack of access to care
- Inequity in treatment
- Biological factors

A survey of 15 Black women with EC showed **cultural barriers**—such as lack of



Actor portrayal

discussion around vaginal bleeding—may make it harder for Black women to seek care even if they are exhibiting symptoms. Many Black women's lack of discussion around EC can lead to a delay in diagnosis, which can result in a later-stage diagnosis when the cancer has spread and may be more difficult to treat.

Due to late-stage diagnosis, more aggressive tumor types, and other healthcare disparities, the **Black community is particularly vulnerable to the disease**. In fact, Black women are twice as likely to die from EC compared to white women. It's vital for all women—and especially Black women—to speak to a doctor if you think you may have any of the risk factors or symptoms of EC.





Learn about your family health history



Know your body and document symptoms as they happen



Visit your gynecologist regularly. After menopause, talk to your gynecologist about how often you should visit, and be sure to take any risk factors you may have into account when determining frequency of visits.

If you are experiencing symptoms, your doctor may use the following tests in order to understand the cause:

- Pelvic examination
- Ultrasound of the uterus
- Biopsy of tissue sample from endometrium
- Dilation and curettage with hysteroscopy

There are currently no routine screening tests for endometrial cancer (EC) so **be sure to discuss any potential symptoms with your doctor right away**. That way, they will be aware of any symptoms you may be having and can follow up appropriately.

TREATMENT APPROACHES FOR EC

- Surgery to remove the uterus (hysterectomy) is the most common treatment for endometrial cancer (EC). It's usually done in a minimally invasive laparoscopic surgery, which has a relatively short recovery period.
- Chemotherapy is a treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing.
- Radiation uses beams of intense energy typically X-rays—to kill cancer cells and may be suggested before or after surgery.
- Hormone therapy may work for some types of EC and is primarily used in young people who wish to have children in the future or if surgery is an unsafe option.
- Targeted therapy focuses on specific weaknesses or mutations present within cancer cells, causing the cancer cells to die while leaving most healthy cells unharmed, and is usually used in the treatment of advanced and recurrent EC.
- Immunotherapy helps your immune system fight cancer cells and may be considered for EC if the cancer is advanced and other treatments have not helped.

WHO IS ON THE CARE TEAM?

If you are diagnosed with endometrial cancer (EC), there are a number of different types of health care providers you may meet during diagnosis, treatment, and beyond. **This group** of individuals is called your "care team."



Gynecologic oncologists are doctors who specialize in both cancer diagnosis/treatment and have gone through special training in operating on cancers of the uterus, cervix, ovaries, fallopian tubes, vulva, and vagina.



Medical oncologists are experts in treating cancer using different medical approaches, like chemotherapy or pharmaceutical drugs.



Oncology nurses specialize in cancer care, and may work with you throughout diagnosis and treatment, help with medical information, assist in managing symptoms and side effects, and answer questions.



Radiation oncologists are experts in using radiation to treat cancer (if this is part of your treatment plan).



Social workers have training in counseling and practical support with things like transportation (to and from appointments, for example), support programs, and more. They can be advocates for you and help you find emotional support. Some social workers specialize in supporting cancer patients.



Patient navigators can help educate you about cancer and facilitate conversations with providers. They can also guide you through diagnosis and treatment, coordinate treatment and care, and help you find financial, logistical, and educational resources.



Registered dietitians can help you cope with some side effects of treatment you may experience and help you maintain healthy eating habits to aid in recovery.

- Jole

Genetic counselors can help determine your risk of getting certain types of cancer based on your personal and family medical history. If you've already been diagnosed with cancer, it can help you better understand how to treat your cancer. These counselors will outline which genetic tests can assess your risk level, explain the testing process, what the tests can and cannot do, and how well they work, and review test results with you once completed.



Palliative care experts are focused not only on end-of-life care, but also on improving the quality of life of people living with cancer. Their goal is to help manage symptoms of cancer and side effects of treatment. They can also help manage mental, physical, emotional, social, and spiritual issues that may come up.

HOW TO COMMUNICATE WITH YOUR DOCTOR

It's important to **clearly communicate your concerns to your doctor**. Here are a few different guiding statements and questions to help facilitate a conversation with your healthcare provider:

If you're experiencing symptoms:

"I've already gone through menopause, but I've been experiencing [heavy / light / very light] [abnormal bleeding / spotting / brownish discharge] of ______ color for the past _____ [weeks / months]."

If you have a personal or family history that puts you at high risk:

"I know I have a higher risk of developing endometrial cancer because of my [PCOS (polycystic ovarian syndrome) / Lynch syndrome / family or personal medical history of breast, uterine or colon cancer]. Can you help me fully understand my inherited risk for endometrial cancer?"

If you've already been diagnosed:

"I've been diagnosed with endometrial cancer, and I know it's important to monitor my symptoms for any changes. I have been experiencing ______ for _____ days/weeks.

"To stay on top of my care plan, can we plan out a schedule for my next follow-up appointments or tests?"

UNDERSTANDING YOUR DIAGNOSIS AND GETTING A SECOND OPINION

Being diagnosed with cancer often comes with a range of emotions—and a sense of urgency to start treatment right away. However, it's important to understand your diagnosis and treatment options, and get answers to questions such as:

- What stage is the cancer?
- What are the most common treatment options?
- Has the cancer spread?
- Is there a clinical trial that may be a good fit?

A second opinion can help confirm your diagnosis, get a different perspective, and determine if there are other treatment options available. After your initial diagnosis, talk to the doctor and **let them know you're going to seek a second opinion**. **It's normal to feel uncomfortable** talking about seeing another physician, but most providers welcome a second opinion because it can provide confirmation of diagnosis and treatment, or even more information. Remember that **it's not uncommon to get a second opinion** and your doctor may even refer you to another provider.



REAL PATIENT STORIES

The following quotes are from real patients and are based on their individual experiences.



Jurline Redeaux 71, California

Proactively spoke with her doctor about symptoms which turned out to be endometrial cancer (EC).

Con't delay, go right away. I was diagnosed with endometrial cancer at 65. I was working part-time as a social worker, in a position that I loved, helping foster youth to reconnect with their families. It was a busy time; however, I made an appointment to see my general practitioner immediately at the first sign of bleeding.



Karen Millman 60, Virginia

Diagnosed with stage IV EC after heavy bleeding sent her to the ER.

At age 56, I was experiencing heavy bleeding, but I wrote it off as a symptom of pre-menopause. I was a busy mom and everything else in life took priority, so I didn't see a doctor. One night I woke up hemorrhaging and wound up in the ER where I learned I had stage IV endometrial cancer. I want other women to learn from my experience. Pay attention to your bodies and don't ignore what could be signs of endometrial cancer.



Nefa-Tari Moore 39, New Jersey

Experienced uterine and ovarian cancer in 2013.

I experienced two months of heavy bleeding, before I decided to go to the emergency room. The ER doctors told me my symptoms may just be a change in my menstrual cycle and stress, but I insisted on more tests and found out I had endometrial cancer. That's why I'm so passionate about encouraging women to advocate for their health and not ignore what could be signs of endometrial cancer. 11



Melany Morrison

55, Texas

Learned Lynch syndrome increased her risk for EC and was diagnosed in 2014.

I shared a story with my gynecologist about an embarrassing moment at the gym when I suddenly felt a gush of blood. But she wasn't amused. She ordered tests for me right away, and I was later diagnosed with endometrial cancer. I also found out I had Lynch syndrome, and I told my daughter about it so she understands her risk. We all need to support the women in our lives by educating and advocating for each other's health.

ADVOCACY GROUPS PROVIDE SUPPORT IN A VARIETY OF WAYS

Spot Her is brought to you by Eisai Inc. in collaboration with advocacy groups Facing Hereditary Cancer Empowered (FORCE), SHARE Cancer Support, Black Health Matters (BHM), Endometrial Cancer Action Network for African-Americans (ECANA), and Foundation for Women's Cancer (FWC). These groups work to **raise awareness**, **provide resources and educational materials, host support groups, and give hope to those impacted by EC**. Their educational and support resources include the following—and more:

Groups and community support

- Support groups
- Facebook groups
- Online message boards
- One-on-one support
- Helplines

Online and inperson education

- Educational webinars
- Blogs
- Articles about EC
- Health summits



Scan the QR code to visit the Spot Her website and access some of our partners' resources.

LIVING WITH ENDOMETRIAL CANCER (EC)

Joining a support group

If you're living with EC, **joining a support group could be a beneficial way to connect with others** who have experienced endometrial or uterine cancers. Scan the QR codes below to learn about the FORCE and SHARE groups and **see how you can participate** in upcoming meetings.







Adjusting to a new normal

After receiving a cancer diagnosis and starting treatment, a lot may change, and **it's important to stay on top of taking care of and advocating for yourself**. You can work with your healthcare team to come up with a plan, which may include:

- Tracking and discussing treatment side effects with your healthcare team
- Monitoring your symptoms
- Taking your medications as prescribed
- Scheduling and getting follow-up tests
- Exploring rehabilitation options, like physical therapy and emotional support
- Making healthy lifestyle changes, like eating healthy and exercising regularly



Use these pages to track your symptoms between appointments, prepare for doctor visits by listing any questions you may have, and write down information during your appointments.

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