Purpose and Goals of ThePatientPath.net

I started ThePatientPath.net on November 9, 2013—just days after I was diagnosed with an aggressive form of uterine (endometrial) cancer of the hereditary type. Today, I am grateful to be a three-year survivor. And I want to hear more of the projected 61,000+ women that will be diagnosed with the disease this year say the same thing.

Yet, although uterine (endometrial) cancer is the fourth most common cancer in US women and the number-one gynecologic cancer—expected to claim almost 11,000 lives this year—it doesn’t get much media attention compared with other cancers. If women do not learn to recognize the risk factors and symptoms, and get timely and proper treatment, their lives may be compromised—and even shortened. And this disease is no longer confined to menopause-age women: younger women stricken with this disease may never bear children.

My mission is to provide informative and inspiring personal stories supplemented with reliable sources of information and support in order to educate, enlighten, encourage, and empower women to be full partners with their healthcare teams as they navigate their own cancer course.

Please join me in raising awareness of this under-discussed disease to promote early detection—the earlier the stage of the cancer, the longer the life of the patient. Together we can help stop uterine (endometrial) cancer from killing the organ that gives us life.

See My Story and More at https://ThePatientPath.net

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hys·te·ri·a
(his-tē'ri-ä), Negative or pejorative connotations of this word may render it offensive in some contexts.

A term derived from the ancient Greek concept of a wandering uterus, denoting maladies involving physical symptoms that seem better explained by psychological factors. The concept of hysteria is historically differentiated into somatization disorder and conversion disorder, both of which are considered types of somatoform disorders in the DSM. The current ICD10, however, places conversion disorder with dissociative disorders, not with somatoform disorders.

See: conversion, psychogenic, psychosomatic.
[G. hyster, womb, from the original notion of womb-related disturbances in women]

Farlex Partner Medical Dictionary © Farlex 2012
Enlightening Women about Uterine Cancer

Some Uterine Cancer Statistics

(See Uterine Cancer Resources; Data May Vary by Reporting Agency and Are Subject to Revision)

1. In 2016, the estimated new cancer cases among US women were projected to be (ACS)
   - Breast (246,660–29%)
   - Lung & bronchus (106,470–13%)
   - Colon & rectum (63,670–8%)
   - Uterine corpus (60,050–7%)

2. In 2016, the estimated cancer deaths among US women were projected to be (ACS)
   - Lung & bronchus (72,160–26%)
   - Breast (40,450–14%)
   - Colon & rectum (23,170–8%)
   - Uterine corpus (10,470–4%) (the 6th most common after pancreas [7%] and ovary [5%])

3. In 2013 data analysis, uterine cancer was first among the 5 main types of gynecologic cancer (CDC)
   - 1,266 were diagnosed with vaginal cancer and 437 (~34.5%) died from it (possibly related to the human papilloma virus [HPV])
   - 4,895 were diagnosed with vulvar cancer and 1,003 (~20.5%) died from it (possibly related to HPV)
   - 11,955 were diagnosed with cervical cancer and 4,217 (~35%) died from it
   - 20,927 were diagnosed with ovarian cancer and 14,276 (~35.5%) died from it
   - 50,560 were diagnosed with uterine cancer and 9,325 (~18.5%) died from it

4. In 2017, 61,380 US women are projected to be diagnosed with uterine cancer and 10,920 to die from it

5. Although some cancers are declining (e.g., lung, colon), others are increasing—including uterine cancer, thought to be related to obesity (ACS); one organization states that making lifestyle changes could prevent 3 out of 5 cases of uterine cancer per year in the US (AICR)

6. The average age of uterine cancer diagnosis is 60, but 5–10% of cases occur in women under 40 (OncoLink)—most likely because of the rise in obesity

7. White women are somewhat more likely to get uterine cancer, but black women are more likely to die from it (see posts about Gwen Ifill on my website)—women of other races tend to present with more advanced disease (ACS) (OncoLink)

8. As yet, no routine screening test for uterine cancer exists—the Pap test does not detect cancer above the cervix (however, research at Johns Hopkins looks promising)

9. The average 5-year survival rate for women with uterine cancer is 82% (ACS); this depends on multiple factors, including the type, stage, and grade of the tumor; “The longer you live, the longer you live” — most recurrences happen in the first 2 years following treatment (SGO)

10. Up to 95% of uterine cancers occur in the uterine lining, or endometrium (ACS, CTCA)—the terms “uterine” and “endometrial” cancer are often used interchangeably, although a small number of uterine cancers arise in the uterine wall, or myometrium (uterine sarcomas)
Illuminating Women about Uterine Cancer

Risk Factors for and Symptoms of Uterine Cancer
(See Uterine Cancer Resources; Factors May Vary by Reporting Agency and Are Subject to Revision)

Many agencies, such as the American Cancer Society, Society of Gynecologic Oncology, and research institutes and hospitals, may present risk factors and symptoms differently—some provide short “highlight” lists, some provide longer lists with explanatory information, and some arrange the information in a different manner. The following listing comes from the Cancer Treatment Centers of America, which has organized the risk factors by subject and has included explanatory material to increase patient understanding. However, all reporting sources address the same underlying causes. Notes in [brackets] and final comments are mine.

If you suspect that you or a loved one might be at risk, or if you notice any unusual change in your gynecologic health, please contact your gynecologist immediately.

Uterine Cancer Risk Factors

Some common risk factors for uterine cancer include:

GENERAL [ESTROGEN FACTORS]

- **Age:** Most women diagnosed with endometrial cancer are over age 50 and have gone through menopause. [However, the average age is 60; women younger than 50 are also being affected.]
- **Number of menstrual cycles:** Women who have more menstrual cycles in their lifetime have an increased endometrial cancer risk. This includes starting periods before age 12 and going through menopause after age 50. [Some sources say after age 52; the average age at menopause is 51.]
- **Childbearing status:** Researchers are still investigating why pregnancy seems to reduce the risk of endometrial cancer. During pregnancy, a woman’s hormonal balance shifts toward progesterone, which reduces estrogen. Irregular menstrual cycles and infertility also may be related to imbalances in estrogen and progesterone levels, and this hormone imbalance may increase the risk.

BODY [ALSO ESTROGEN]

- **Obesity:** Fat tissues tend to produce higher levels of estrogen, particularly after menopause, which places older, overweight women at greater risk for this type of uterine cancer. [DIABETES]
GENETICS

- **Family history:** Women with a family history of endometrial, colon, or ovarian cancer, including a genetic syndrome called hereditary nonpolyposis colorectal cancer (HNPCC), may be at a higher risk of developing endometrial cancer. [LYNCH SYNDROME]

OTHER CONDITIONS [LIFESTYLE; PERSONAL HEALTH HISTORY]

- **Diabetes:** Endometrial cancer is more prevalent in women with diabetes. Doctors think this may have to do with the higher obesity rates found in patients with type 2 diabetes. [OBESITY]
- **Complex atypical endometrial hyperplasia:** This precancerous condition is an increased growth of the uterine lining and may become cancerous if left untreated. [MAY HAVE HAPPENED TO ME]
- **Ovarian tumors and syndromes:** Certain ovarian syndromes, such as polycystic ovarian syndrome (PCOS), and ovarian tumors can increase estrogen levels and increase a woman’s risk of developing this type of uterine cancer.

PREVIOUS TREATMENT [ESTROGEN; ALSO PELVIC RADIATION]

- **Estrogen replacement therapy:** Replacing estrogen without progesterone after menopause may increase a woman’s risk of developing this type of uterine cancer.
- **Tamoxifen:** Women who are treated with the breast cancer drug tamoxifen have an increased risk of developing endometrial cancer [IT ACTS AS AN ESTROGEN IN THE UTERUS]

Uterine Cancer Symptoms

*Common uterine cancer symptoms may include:*

- **Vaginal bleeding or spotting:** This includes vaginal bleeding between periods, prolonged periods, or bleeding after intercourse or after menopause.
- **Abnormal vaginal discharge:** Some women experience a watery or bloody discharge as a symptom of their disease, though this is often a sign of infection or other non-cancerous conditions.
- **Pelvic pain or pressure:** Pain during intercourse or at other times may be a uterine cancer symptom, or the sign of a less serious condition. Women who experience unexpected vaginal bleeding, spotting or unusual discharge should discuss these symptoms with their gynecologist.

Bottom Line: The Risks Point to Two Types of Endometrial Cancer

Depending on your history and tumor staging after surgery, endometrial cancers fall into two main types:

**Type 1** endometrial cancers are thought to be caused by excess estrogen and are usually not very aggressive (do not spread to other tissues quickly). About 80% of endometrial cancers fall into this type.

**Type 2** endometrial cancers don’t seem to be caused by too much estrogen and are more aggressive (more likely to grow and spread outside the uterus). Of the 20% of these cancers, most are due to genetics.

If You Think You Are at Risk . . .

If you have abnormal vaginal bleeding, discharge, or pain, SEE YOUR GYNECOLOGIST IMMEDIATELY. Regardless of your age, abnormal bleeding is the primary symptom of uterine cancer. Discuss a referral to a gynecologic and the need for a biopsy of the endometrium—not just a pelvic exam or ultrasound.

If you have a personal and/or family history of cancer, consider genetic counseling and testing.
What Happened to Me

Risk factors and symptom:

In September 2013, I had several risk factors and one major symptom: age 61, overweight, history of atypically thickened uterine lining with benign polyps, a family history of colon cancer (my dad, his grandmother), and abnormal vaginal bleeding. (I had a pelvic ultrasound and a D&C [dilatation and curettage] in October 2013, followed by cancer surgery in December 2013 and radiation in 2014.)

In November 2012, my Pap test was normal, and a pelvic ultrasound showed some endometrial thickening and a fibroid. We discussed my using Vagifem, which can cause uterine cancer as it is made of unopposed estrogen—it could make the fibroid larger and cause a more thickened endometrial lining. This would mean I’d need to be checked every four months and might need a D&C, so I decided not to use it.

In May 2007, I had slight vaginal bleeding, and an ultrasound showed a polyp. A D&C was performed at that time, and the polyp was benign. So I wasn’t alarmed when I had vaginal bleeding in September 2013, assuming I’d just need another D&C.
Preliminary diagnosis following D&C, October 28, 2013:

Specimen 1, Endocervical Curettage, Polyp: Endometrial Adenocarcinoma, Endometrioid Type, Grade 2; Benign Endocervical Polyp

Specimen 2, Endometrial Curettage: Endometrial Adenocarcinoma, Endometrioid Type, Grade 2

Interpretation:

Endometrial cancer, which arises from the lining (endometrium) of the uterus, accounts for about 95% of all uterine cancers (ACS, CTCA). (Only 5% or fewer uterine cancers arise from the muscle layer of the uterus, or myometrium, and are typically called uterine sarcomas.)

Most endometrial cancers are adenocarcinomas, which form in glandular cells that make and release mucus and other fluids. The most common type of adenocarcinoma is endometrioid adenocarcinoma, which contains tumor cells differentiated into glandular tissue with little or no connective tissue (stroma). Endometrioid adenocarcinoma accounts for about 75% of all uterine cancers, is commonly detected early, and has a high cure rate when detected early (MSKCC)—depending on the final (postsurgical) diagnosis.

The Specimen 1 portion of the diagnosis was questionable, but the Specimen 2 diagnosis was definite. An MRI (magnetic resonance imaging) performed on November 12, 2013 showed that the cancer cells noted in Specimen 1 most likely did not arise in the cervix, but were pulled down from my uterus during the D&C.

Final diagnosis following surgery, December 13, 2013:

I had a total da Vinci® robot-assisted laparoscopic hysterectomy (uterus and cervix removed), bilateral salpingo-oophorectomy (tubes and ovaries removed), pelvic and para-aortic lymph node dissection (24 lymph nodes removed), peritoneal lavage (abdominal cavity "washing"), and cystoscopy and bladder lavage.

Specimen 1, Uterus: Endometrial Adenocarcinoma of the Endometrioid Type, Stage 1B , Grade 3, Type 2

Specimen 2, Cervix: Benign Polyp

Specimen 3, Myometrium: Small Leiomyoma (Benign Fibroid)

Specimens 4–7, Fallopian Tubes and Ovaries: Mild Chronic Salpingitis and Benign Cyst, Right Fallopian Tube; Left Fallopian Tube and Ovaries Negative for Tumor

Specimens 8–31, Lymph Nodes (24): All Negative for Tumor

Interpretation (ACS):

As noted above, endometrial cancer accounts for about 95% of all uterine cancers, most endometrial cancers are adenocarcinomas, and the most common type of adenocarcinoma is endometrioid adenocarcinoma, which accounts for about 75% of all uterine cancers. So far, this is a common diagnosis.

The stage of the tumor is based on the extent of the mass and whether it has invaded other tissues or lymph nodes. My tumor was large (4.5 x 3.5 x 2.5 cm) and had almost completely filled the uterus. It had also invaded the uterine muscle layer (myometrium) by 68%—but fortunately, not beyond it, and not into the lymph nodes. Thus, it is considered Stage 1B (some organizations might classify it as Stage 1C).

More worrisome was the Grade 3 aspect of the diagnosis. Although my cancer was relatively common, the cells in my tumor did not look like normal endometrium, and so was called "poorly differentiated" or "high grade." In Grade 3 tumors, less than half of the cancerous tissue does its job of forming glands and may appear "bizarre." These cancers tend to be aggressive than lower-grade cancers.
Grades 1 and 2 endometrioid cancers are considered **Type 1** endometrial cancers, likely caused by excess **estrogen**. These cancers are usually not very aggressive and do not spread to other tissues quickly. A smaller number (20%, OncoLink) of endometrial cancers are **Type 2**, which are more likely to grow and spread outside the uterus and have a poorer outlook than Type 1 cancers. They don’t seem to be caused by excess estrogen, but by other factors, such as **genetic predisposition** or spontaneous mutation. **Type 2 endometrial cancers include** papillary serous carcinoma, clear-cell carcinoma, undifferentiated carcinoma, and **grade 3 endometrioid carcinoma**. Although my surgeon didn’t discuss it with me at the time, the high grade of my tumor meant that I had a Type 2 cancer that is likely caused by hereditary factors (see below).

**Radiation:**

Because of the diagnosis, it was recommended that I have vaginal radiation treatments, called “brachytherapy,” to prevent any remaining microscopic cells from causing a recurrence either in the vaginal cuff or, if they migrated, elsewhere in the body. The reduction in risk was not considered great enough compared with the side effects of external pelvic radiation (such as lymphedema) to warrant this additional treatment, and chemotherapy was mentioned but not recommended.

**Complications:**

For about two-and-a-half weeks, I had extensive lymphatic fluid drainage following surgery, but fortunately this healed after my system learned to reroute the lymph now that the nodes were gone. Over time, additional changes will likely continue occurring secondary to radiation, depending on when the cells regenerate in different tissues. I have had vaginal and rectal symptoms and bladder and rectal prolapse. My entire story is on ThePatientPath.net.

**Hereditary factors:**

Damaged or defective DNA (mutations) can alter the functioning of genes that control cell growth. If these genes are damaged, out-of-control growth may result in cancer. Sometimes, endometrial cancer and colon cancer may seem to “run in a family.” Some of these families have a higher risk for these cancers because they have an inherited defect in certain genes that normally help repair damage to DNA with enzymes. If the repair enzymes are not working properly, damage to DNA is more likely to persist and cause cancer. Similar DNA repair defects have also been found in endometrial cancer cells from some patients without an inherited tendency to develop this disease. (ACS)

**More than 2,000 (about 20%) cases of endometrial cancer each year may have a hereditary cause** (SGO). In December 2016 at my three-year cancer checkup, I discussed some gastrointestinal symptoms and changes with my doctor and reminded him that my father had had colon cancer. He sent my preserved uterus back to the lab, and the preliminary results indicate the possibility of Lynch syndrome. Currently, I am undergoing genetic counseling and testing for this condition and will report the results next month.

**Caution for You**

1. Whatever your age, see your gynecologist immediately if you notice any unusual vaginal bleeding or discharge, which may start as a watery, blood-streaked flow that gradually contains more blood, or if you experience difficult or painful urination, pain during intercourse, or pelvic pain and/or a mass.

2. Discuss having a second-opinion consultation with a gynecologic oncologist, who would very likely do a biopsy—not just a pelvic examination or an ultrasound. The **Society of Gynecologic Oncology (SGO)** has a referral service.

3. If you have a personal or family history of cancer, consider genetic counseling and testing.
Illuminating
The Patient Path

Enlightening Women about Uterine Cancer

Some Uterine Cancer Resources

These resources are intended to supplement—not replace—the advice of your clinical team.

- **American College of Obstetricians and Gynecologists (ACOG)** – Endometrial Cancer: [https://www.acog.org/Patients/FAQs/Endometrial-Cancer](https://www.acog.org/Patients/FAQs/Endometrial-Cancer)
- **Centers for Disease Control and Prevention** – Uterine Cancer: [https://www.cdc.gov/cancer/uterine/](https://www.cdc.gov/cancer/uterine/)
- **Memorial Sloan Kettering Cancer Center (MSKCC)** – Uterine (Endometrial) Cancer: [https://www.mskcc.org/cancer-care/types/uterine-endometrial](https://www.mskcc.org/cancer-care/types/uterine-endometrial)
- **Peach Society** – Facebook: [https://www.facebook.com/PeachSociety/?fref=ts](https://www.facebook.com/PeachSociety/?fref=ts)
- **Peach Outreach** – Facebook: [https://www.facebook.com/PeachOutreach/](https://www.facebook.com/PeachOutreach/)
- **Alive And Kickn, A Hereditary Cancer Foundation** – Facebook: [https://www.facebook.com/AliveAndKickn/?pnref=lhc](https://www.facebook.com/AliveAndKickn/?pnref=lhc)