UNDERSTANDING
Your Diagnosis of Endometrial Cancer

A STEP-BY-STEP GUIDE

INTRODUCTION

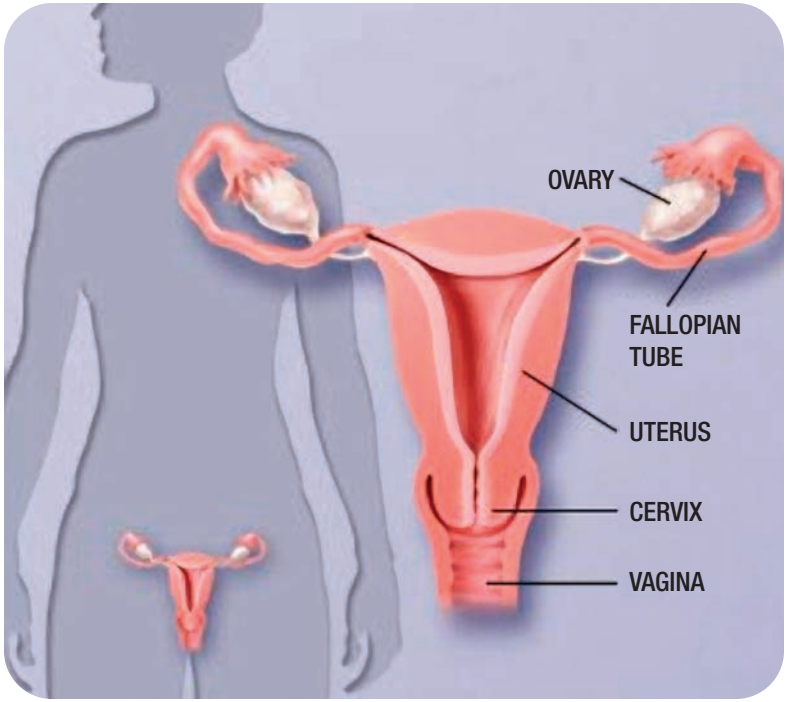
This guide is designed to help you clarify and understand the decisions that need to be made about your care for the treatment of endometrial cancer. It is hoped that by providing useful information about treatment options and identifying important questions that you might want to discuss with your physician and treatment team, you will have a better understanding of your care. There is room in this notebook to make notes, record essential information and list important phone numbers. There also is a calendar to help you keep track of your appointments and other important dates.

The purpose of this guide is to help women diagnosed with endometrial cancer gain knowledge about treatment options and what questions to ask at each step of the process.

UNDERSTANDING YOUR DISEASE

What is the endometrium?

The uterus is a muscular organ sitting in the pelvis between the bladder and rectum. The uterus has a central cavity or pocket in it that is lined by a unique surface called the endometrium. During the reproductive years, the endometrium cycles under the influence of hormones produced by the ovaries. In normal menstrual cycles, the endometrium is shed with each menstrual period.



WebMD 2002

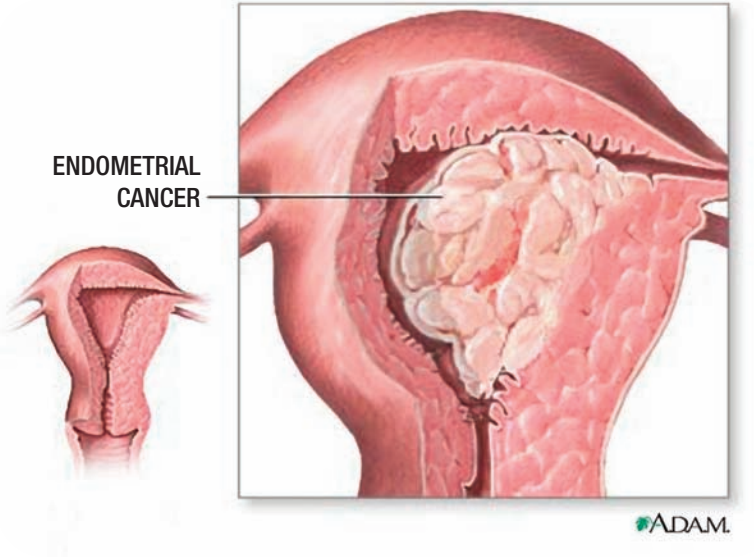
Most endometrial cancers occur in women after menopause. The most common warning sign is any bleeding after menopause.

What is endometrial cancer?

Like many tissues in the body, the endometrium can undergo cancerous changes, and when this happens, an endometrial cancer results. The cancerous cells may be found only on the surface, but also may grow into the underlying uterine muscle wall or, less commonly, spread outside of the uterus to the ovaries, fallopian tubes, vagina, lymph nodes or abdominal cavity.

Most endometrial cancers occur in women after menopause. The most common warning sign is any bleeding after menopause. Younger women may develop endometrial cancer and may notice irregular or heavy vaginal bleeding.

Risk factors for endometrial cancer include obesity, hypertension, diabetes, use of estrogen without progestins, tamoxifen use and late menopause. Women who have not been pregnant also have a slightly higher risk for endometrial cancer. Some women diagnosed with endometrial cancer have none of these risk factors, while others may have several.



SELECTING THE RIGHT PHYSICIAN

It is important to select a physician whom you trust and who is best qualified to provide expert care.

If possible, you should receive your care from a gynecologic oncologist because these specialists only take care of women with cancers like endometrial cancer. They begin their training as obstetrician-gynecologists and then receive 3–4 years of advanced training in gynecologic cancers, including advanced training in surgery and the use of chemotherapy.

The Gynecologic Cancer Foundation's Web site, the Women's Cancer Network (www.wcn.org) contains a list of gynecologic oncologists by zip code in the "find a doctor" section.

If possible, you should receive your care from a gynecologic oncologist because these specialists only take care of women with cancers like endometrial cancer.

DIAGNOSING ENDOMETRIAL CANCER

When women experience symptoms that could lead to a diagnosis of endometrial cancer, an endometrial biopsy should be performed. Sometimes an ultrasound study is also performed.

When women experience symptoms that could lead to a diagnosis of endometrial cancer, an endometrial biopsy should be performed. Sometimes an ultrasound study is also performed.

A biopsy is the removal of a small piece of tissue for analysis and is the only way to accurately diagnose endometrial cancer. It can be done in the physician's office or in the operating room.

In cases where there is a cancer, the tumor can be classified by its appearance under the microscope and described by its "histologic type" and "tumor grade."

The **histologic type** describes the appearance of the cancer cells and how they are arranged. The **grade** is a description of how normal the individual cells appear.

Cells that are most similar to normal endometrial cells are classified as grade 1 and cells that are more abnormal are classified as grade 3. Those in the middle are called grade 2.

Information on tumor histologic type and grade are useful (although not perfect) predictors of the aggressiveness of the tumor.

My tumor histologic type is

_____

_____

_____

The grade is

_____

_____

_____

TREATMENT OPTIONS

The most common treatment for endometrial cancer is surgery, although radiation therapy is sometimes used before surgery to shrink the cancer. Although uncommon, radiation therapy is sometimes used instead of surgery to treat early-stage endometrial cancer.

Which procedure is best for me?

_____

_____

Who is the gynecologic oncologist involved in my care?

_____

_____

_____

_____

Surgery

- For most patients, surgery with removal of the uterus (hysterectomy) and removal of the ovaries is the standard treatment.

- Many surgeons recommend "surgical staging" in addition to a hysterectomy. This includes removal of lymph nodes (called a lymph node dissection) from the areas where cancer spread would most likely occur outside the uterus. The likelihood that the cancer has spread outside the uterus is related to a number of factors, such as histologic type, tumor grade and how deep the cancer has grown into the uterine wall. In some cases, lymph node surgery is not recommended and the risk of this surgery should be balanced by the risk of having the cancer spread to the lymph nodes. Your doctor should explain why or why not a lymph node dissection will be performed.

- The surgery is frequently performed through an incision on the belly (abdomen). Some surgeons also perform the surgery by laparoscopy (minimally invasive surgery). Your surgeon will explain which approach is most suitable for you.

- Following surgery, most patients will have a catheter (tube) in their bladder to drain urine for the first 1–2 days after surgery.

- The typical length of hospital stay following hysterectomy is 2–4 days.

- Most patients will recover sufficiently to return to normal activities or work within 4–8 weeks.

After surgery

- Patients with cancer are classified by "stage" of their disease. Stage is a way to classify patients with similar disease factors so that similar groups of patients may be compared. The stage assignment is also important to determine if additional treatment is needed.
  - **Stage I disease** is confined to the uterus. Stage I is sub-divided depending on how deep the cancer spreads into the underlying uterine muscle wall.
  - **Stage II disease** has spread to the cervix (the opening of the uterus that connects to the vagina).
  - **Stage III disease** has spread outside of the uterus to the ovaries/fallopian tubes, to the outer surface covering of the uterine wall (called the serosa) and/or to lymph nodes. Patients with floating cancer cells identified in a sample of fluid from the pelvis or abdomen are also classified as having Stage III disease.
  - **Stage IV disease** has spread into the bladder, rectum, abdominal cavity or outside of the abdomen surfaces (lung, liver).

What is my stage?

_____

_____

- Most patients will not require any additional treatments other than careful observation. You will be seen periodically by your doctors to review how you are feeling and to perform an examination. Typically, these special cancer followup examinations take place for 5 years following your first surgery.

- You should let your doctor know if you experience vaginal bleeding, increasing pelvic or abdominal pain, bloating, nausea/vomiting, or changes in urinating/bowel movements. Everyone has an occasional ache and pain. Symptoms which persist or worsen for more than a few weeks should be evaluated.

How often will I need to be seen?

_____

_____

What tests will be done, if any, on a routine basis?

_____

_____

_____

_____

If other treatment is recommended

- Some patients will have certain conditions that are thought to increase the chances of the cancer returning (recur) when treated by surgery alone. In these cases, additional treatments (radiation, chemotherapy or hormones) are recommended.

Do you recommend any additional treatments to fight my cancer?

_____

_____

_____

_____

_____

_____

_____

Radiation therapy

Radiation therapy (also called radiotherapy) uses high-energy x-rays, or other types of radiation, to kill cancer cells or stop them from growing. It is used after surgery to kill any cancer cells that may have been left behind (called adjuvant therapy).

Two types of radiation therapy are used to treat endometrial cancer:

- **External radiation therapy** uses a machine that directs the x-rays toward a precise area on the body. The therapy is usually given every day for about 6 weeks. It does not hurt and only takes a few minutes each day. You can be treated at a clinic, hospital or radiation oncology office.
- **Internal radiation therapy** (also called brachytherapy) involves placing a small capsule of radioactive material inside the vagina. This procedure can be performed either on an inpatient or outpatient basis, depending upon your treatment team's recommendation.

Radiation therapy is provided by a radiation oncologist, a specialist trained in the treatment of cancer with various types of radiation. If your doctor feels that you might benefit from additional treatment, you will be asked to see a radiation oncologist in consultation to get advice, and, when needed, to facilitate any radiation treatment.

What is the role of radiation therapy for me?

_____

_____

_____

What types of radiation are most commonly recommended for patients like me?

_____

_____

_____

Roughly, how soon after surgery would I start treatments?

_____

_____

_____

How long does it take to complete the treatments?

_____

_____

_____

Chemotherapy

Chemotherapy is the use of drugs to kill cancer cells. Chemotherapy for endometrial cancer is usually given intravenously (injected into a vein). You may be treated in the doctor's office or the outpatient part of a hospital.

The drugs travel through the bloodstream to reach all parts of the body. This is why chemotherapy can be effective in treating endometrial cancer that has spread beyond the uterus. However, the same drugs that kill cancer cells may also damage healthy cells.

Chemotherapy is usually given in cycles. Periods of chemotherapy treatment are alternated with rest periods when no chemotherapy is given. Side effects are common, but your treatment team will help you to find ways to manage the side effects.

Do you recommend any chemotherapy for me?

_____

_____

Why or why not would I benefit from chemotherapy?

_____

_____

_____

_____

The chemotherapy recommended for me is

_____

_____

When will I start?

_____

_____

How often will the treatment be given?

_____

How many treatments (cycles) will be needed?

_____

_____

The most common side effects are

_____

_____

_____

_____

Hormone therapy

In some endometrial cancers, based upon cancer histology and grade, an option exists to use hormone therapy to treat the cancer. The use of hormones in this setting is different from hormones used to treat symptoms related to menopause (commonly called "hormone replacement therapy"). Because the growth of some types of endometrial cancer can be slowed or blocked by the use of certain types of hormones, hormone treatment (such as progestins) may be an option for certain patients. In general, these agents are taken as a pill, but can be given as a shot.

If this option is felt to be safe for you, close follow-up, including repeated biopsies, is needed. Your doctor will explain why or why not hormone therapy to treat the cancer would be a good option for you, and what additional evaluations and treatments may be required.

Do you recommend any hormone therapy for me?

_____

_____

_____

When will I start?

_____

_____

_____

The hormone therapy recommended for me is

_____

_____

_____

The most common side effects are

_____

_____

_____

CLINICAL TRIALS

Some woman undergoing treatment for endometrial cancer might benefit from participation in clinical trials.

Clinical trials are the paths to create and test treatments that are more effective and less toxic. New treatments are tested in a series of trials known as Phase I, Phase II and Phase III. The Federal Drug Administration (FDA) checks and approves new cancer drugs and other treatments. But they only do that after the final, Phase III trials, have shown better results or less side effects compared to standard treatments. Likewise, new ways to do surgery are recommended after Phase III trials. Results must show that the new methods are more safe, tolerable or effective.

Ask your doctor about clinical trials that may be appropriate for you.

More information about clinical trials can be found on the Gynecologic Cancer Foundation's (GCF) Women's Cancer Network Web site (www.wcn.org).

Is there a clinical trial for which I am eligible?

_____

_____

SPECIAL CASES

I am young, and I do not want a hysterectomy.

Younger patients who have endometrial cancer sometimes are interested in preserving the opportunity to become pregnant. Removing the uterus (hysterectomy) prevents patients from getting pregnant.

In some endometrial cancers (based on cancer histology and grade), an option exists to use hormone therapy to reverse the cancer. If this option is felt to be safe for you, close follow-up, including repeated biopsies, is needed. Your doctor will explain why or why not hormone therapy would be a good option for you, and what additional evaluations and treatments are required.

The risks (cancer spreading, delay in treatment) and benefits (opportunity to get pregnant) must be considered thoughtfully by you and your doctor.

I have serious health problems making surgery more difficult or dangerous.

In some cases, surgery brings such high risks of injury or death to the patient that alternative methods for managing the endometrial cancer must be considered. In these rare cases, radiation therapy without surgery or hormonal therapy might be considered. In some cases, using only a vaginal hysterectomy (removing the uterus through the vagina without an abdominal incision) is an option. Your doctor will explain the options and help to design a care plan for you that meets your particular needs.

My cancer has spread to areas outside of the uterus.

In some cases, the endometrial cancer has spread outside of the uterus to other parts of the body for which surgery is less likely to be effective (liver, lung, neck lymph nodes). For these patients, individualizing the treatments is common. In some cases, chemotherapy, hormone therapy or radiation therapy is used without surgery. In some cases, a hysterectomy is considered to remove the uterus and stop vaginal bleeding. Your doctor will outline a treatment plan for you.

FINAL MESSAGES

As you go through cancer treatment, be patient with yourself. Understand that a return to your full life will take time. Your treatment team can guide you through the difficulties that you will face if they know what is troubling you. Talk openly about the things that bother you. Give yourself the time you need.

Advance directives can be a helpful tool for clarifying your medical care wishes. We encourage both patients and families to complete one. Your healthcare team is available for guidance on this matter.

Nurture hope. It's up to you to take charge of your reaction even as you face the unknown of cancer. Hope helps you see the positive aspects of life.

If you have inner spiritual beliefs, reach out to your religious or support community to give you additional guidance to face each day and live fully.

Seek support. There are many resources available to help you deal with the physical, sexual or emotional issues you may have as a result of cancer and its treatment. Specially trained counselors can help you deal with the impact of cancer on your life. Support groups are another good resource. People who are facing a situation similar to yours can come together to share their experiences and give one another advice and emotional support. To find support services in your area, talk with a member of your treatment team, or contact the resources listed on the following page. Remember you are surrounded by a devoted healthcare team so let us be at your side.

RESOURCES FOR MORE INFORMATION

American Cancer Society
(800) 227–2345
www.cancer.org

Cancercare
(800) 813–4673
www.cancercare.org

Cancer Hope Network
(877) 467–3638
www.cancerhopenetwork.org

The Elizabeth Gillespie Fund for Life
www.fundforlife.org

Gynecologic Cancer Foundation
(312) 578–1439
www.thegcf.org

National Cancer Institute
Cancer Information Services
(800) 422–6237
www.cancer.gov

Women's Cancer Network Web Site
(312) 578–1439
www.wcn.org

The Gynecologic Cancer Foundation publishes a companion brochure titled "Understanding Endometrial Cancer: A Woman's Guide." The brochure may be ordered through the GCF Web site at www.thegcf.org or by calling GCF's Information Hotline at 800.444.4441.

IMPORTANT PHONE NUMBERS

Gynecologic oncologist's office

_____

appointments

_____

after hours calls

Radiation oncologist

_____

Chemotherapy/infusion center

_____

My pharmacy

_____

APPOINTMENT DATES

First appointment _____

Date of surgery _____

TWO-YEAR CALENDAR

Appointment Date	Year #	Problems	Tests Performed

Appointment Date	Year #	Problems	Tests Performed

Appointment Date	Year #	Problems	Tests Performed

Appointment Date	Year #	Problems	Tests Performed

Appointment Date	Year #	Problems	Tests Performed

Appointment Date	Year #	Problems	Tests Performed

Appointment Date	Year #	Problems	Tests Performed

Appointment Date	Year #	Problems	Tests Performed

Appointment Date	Year #	Problems	Tests Performed

Appointment Date	Year #	Problems	Tests Performed

230 W. Monroe, Suite 2528
Chicago, IL 60606

info@thegcf.org
www.thegcf.org
www.wcn.org
www.cervicalcancercampaign.org

Brochure content developed by the Gynecologic Cancer Foundation. Printing made possible by Myriad Genetic Laboratories, Inc.

UDEC-E-2009