

A silhouette of a woman sitting in profile, facing right, against a purple background. The woman is wearing a dark top and pants. The background is a gradient of purple, with a darker shade on the right and a lighter shade on the left. The woman's silhouette is dark, almost black, and she is sitting with her legs crossed at the ankles.

U NDERSTANDING Endometrial Cancer

A WOMAN'S GUIDE

CONTENTS

INTRODUCTION	1
ENDOMETRIAL CANCER: AN OVERVIEW	2
WORKING WITH YOUR TREATMENT TEAM	4
TREATMENT	6
LIVING WITH CANCER THERAPY	12
TIPS FOR COPING	15
FINAL MESSAGES	17
RESOURCES FOR MORE INFORMATION.....	back cover

“Understanding Endometrial Cancer: A Woman's Guide” was developed by the Gynecologic Cancer Foundation (GCF) through the generous support of the Elizabeth Gillespie Fund for life. GCF was formed by the Society of Gynecologic Oncologists in 1991 to raise funds to ensure public awareness of gynecologic cancer prevention, and the need for early diagnosis and proper treatment of gynecologic cancers.

GCF administers the Elizabeth Gillespie Fund for Life which was formed in memory of Elizabeth Gillespie to continue her commitment to early detection, proper treatment and diagnosis of uterine cancer.

For more information about GCF, log on to www.thegcf.org. For more information about the Elizabeth Gillespie Fund for Life, log on to www.fundforlife.org.

INTRODUCTION

You have received a diagnosis of endometrial cancer, sometimes called uterine cancer. The amount of information you receive at the time of diagnosis can feel overwhelming. All at once, you may feel there are many unanswered questions, decisions to be made, and so much information to be understood.

A team of healthcare professionals will work with you throughout your treatment process. Each of them has an important job, but the most vital member of the team is you. In order to play an active role during your treatment, you should try to learn as much about endometrial cancer as possible.

This booklet will take you through the basics of what you need to know about endometrial cancer. It will introduce you to the people who may be part of your treatment team. Also, it will identify the different types of treatment for endometrial cancer. Hopefully this information will help prepare you to talk with your treatment team and to feel more confident about your treatment plan.

ENDOMETRIAL CANCER: AN OVERVIEW

Cancer occurs when cells in an area of the body grow abnormally. Endometrial cancer is cancer of the lining of the uterus (called the endometrium). The uterus (or womb) is where a baby grows during pregnancy. The fallopian tubes on both sides of it connect it to the ovaries, and the cervix connects it to the vagina. These reproductive organs are located in the pelvis, close to the bladder and rectum.

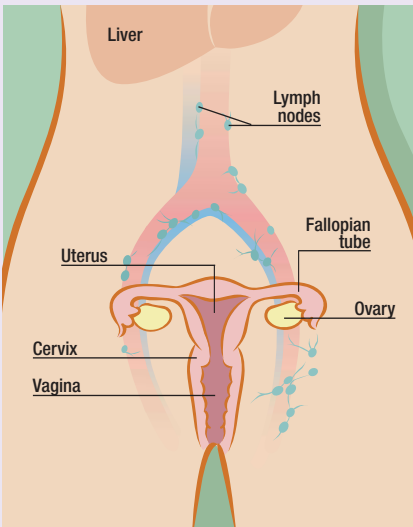
The endometrium is the inside lining of the uterus that grows each month during the childbearing years. It does this so that it will be ready to support an embryo if a woman becomes pregnant. If pregnancy does not occur, the endometrium is shed during the menstrual period.

Why do women get endometrial cancer? One of the strongest and most common risk factors for the development of endometrial cancer is obesity. Women who are obese have higher circulating levels of estrogen, which increases their risk for endometrial cancer. Tamoxifen use and taking estrogen alone are also risk factors. About 75% of women diagnosed with endometrial cancer have already gone through menopause.

A small percentage of women develop endometrial cancer due to inheriting a predisposition for this cancer from their mother or father. While rare, these families have a high frequency of endometrial, colon and ovarian cancer. If you have relatives with endometrial, colon and ovarian cancer you should see a genetics specialist.

STAGING

When endometrial cancer is diagnosed, it is vital to determine if the cancer has spread beyond the endometrium. Your treatment team may do more tests to determine if the cancer has spread. In addition, during surgery, certain additional steps should be performed to determine the extent of disease. This process is called staging. Staging helps to determine the exact extent of your cancer and what treatment plan is best for you.

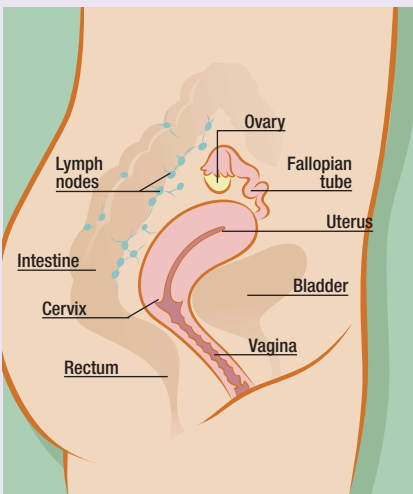


Endometrial cancer is grouped into four stages.

Stage I: The cancer is found only in the uterus. It has not spread to the cervix (opening of the uterus).

Stage II: The cancer has spread from the uterus to the cervix (opening of the uterus), but it has not gone any further.

Stage III: The cancer has spread outside the uterus itself. It may have spread to nearby lymph nodes, ovaries, fallopian tubes and vagina, but it has not gone outside the pelvic area. It has not spread to the bladder or rectum.



Stage IV: The cancer has spread into the bladder or rectum and/or to other body parts outside the pelvis, such as the abdomen or lungs.

WORKING WITH YOUR TREATMENT TEAM

During your treatment, you will come in contact with many health care professionals. These people make up your treatment team. They will work with each other and you to provide the special care you need. Your treatment team may include some of the health care professionals listed below:

Oncologist the cancer specialist who will coordinate your care. There are different types of oncologists. Your treatment team may include a:

- ▶ **Gynecologic oncologist** who is specially trained in the comprehensive surgical care and medical treatment of female reproductive cancers like endometrial cancer. A gynecologic oncologist can manage your care from diagnosis to completion of treatment.
- ▶ **Medical oncologist** who specializes in using drug therapy (chemotherapy) to treat cancer.
- ▶ **Radiation oncologist** who specializes in using radiation therapy to treat cancer.

Oncology nurse a nurse who specializes in cancer care. An oncology nurse can work with you on every aspect of your care, from helping you understand your diagnosis and treatment to providing emotional and social support.

Social worker a professional trained in counseling and practical assistance, community support programs, home care, transportation, medical assistance, insurance and entitlements. They are very helpful advocates, especially when you are first diagnosed and unsure what to do next.

Hospital chaplain many clinics and hospitals offer cancer patients the support of a chaplain during their cancer care.

Talking with your treatment team

You deserve expert advice and treatment from your treatment team. Be sure to talk openly about your concerns with the members of your treatment team. Let them know what is important to you. If it is hard for you to speak for yourself, these tips may help:

- Make a list of questions before your visit. Ask the most important questions first.
- Take notes or ask if you can tape record your medical office visits and phone conversations.
- If you don't understand something, ask the treatment team member to explain it again in a different way.
- If possible, bring another person with you when you meet with members of your treatment team to discuss test results and treatment options.

TREATMENT

Endometrial cancer may be treated with surgery, radiation therapy, chemotherapy, or hormonal therapy. Depending on your situation, your treatment team may recommend using a combination of treatments to treat your cancer.

Your specific treatment plan will depend on several factors, including:

- ▶ The stage of your cancer
- ▶ The size and location of your cancer
- ▶ Your age and general health

All treatments for endometrial cancer have side effects. Most side effects can be managed or avoided. Some treatments may affect your sexuality. (For more information about sexual side effects, see page 14.) Some treatments may affect your ability to have children in the future.

Before beginning treatment, it is important to learn about the possible side effects and talk with your treatment team members about your feelings or concerns. They can prepare you for what to expect and tell you which side effects should be reported to them immediately. They can also help you find ways to manage the side effects you experience.

SURGERY

The most common treatment for endometrial cancer is surgery. Several types of surgery can be performed.

Hysterectomy: involves removal of the uterus and cervix and is the standard procedure for treating endometrial cancer. The uterus and cervix can be removed in one of three ways:

- **Total abdominal hysterectomy:** the uterus and cervix are taken out through an incision in the abdomen.
- **Radical abdominal hysterectomy:** in addition to the uterus and cervix, the tissue next to the uterus and cervix, as well as part of the upper vagina, are also removed
- **Laparoscopic-assisted vaginal hysterectomy:** the uterus and cervix are taken out through the vagina with the assistance of a laparoscope (a small tubelike viewing instrument) that is placed through the abdomen via a small incision.

For those patients with multiple medical problems and who are not healthy enough to undergo an extensive surgical procedure, a vaginal hysterectomy can be performed.

In most cases, both ovaries and both fallopian tubes must also be removed. This procedure is called a **bilateral salpingo-oophorectomy**.

Lymph nodes in the abdomen and pelvis may also be taken out to see whether they contain cancer.

Side effects of surgery

Some discomfort is common after surgery. It often can be controlled with medicine. Tell your treatment team if you are experiencing any pain. Other possible side effects are:

- ▶ Infection
- ▶ Wound problem
- ▶ Anemia
- ▶ Leg swelling (lymphedema)
- ▶ Blood clots
- ▶ Difficulty urinating or constipation
- ▶ Shortening of the vagina

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. Radiation therapy can be used:

- ▶ Instead of surgery to treat early-stage endometrial cancer although this is uncommon
- ▶ Before surgery, to shrink the cancer (called neoadjuvant therapy)
- ▶ 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 teams' recommendation.

Side effects of radiation

The side effects of radiation therapy depend on the dose used and the part of the body being treated. Common side effects include:

- Dry, reddened skin in the treated area
- Fatigue
- Diarrhea
- Discomfort when urinating
- Narrowing of the vagina
- Anemia

Most of these side effects are temporary. Be sure to talk with your treatment team members about any side effects you experience. They can help you find ways to manage them.

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. Some side effects may still occur.

Side effects

Each person responds to chemotherapy differently. Some people may have very few side effects while others experience several. Most side effects are temporary. They include:

- ▶ Nausea
- ▶ Loss of appetite
- ▶ Mouth sores
- ▶ Increased chance of infection
- ▶ Bleeding or bruising easily
- ▶ Vomiting
- ▶ Hair loss
- ▶ Fatigue

HORMONE THERAPY

Some types of endometrial cancer need hormones to grow. In these cases, hormone therapy is a treatment option. Hormone therapy removes female hormones or blocks their action as a way of preventing endometrial cancer cells from getting or using the hormones they may need to grow. It is usually taken as a pill, but can be given as a shot.

Side effects of hormone therapy

The side effects of hormonal therapy depend on the type of hormones being used. Some women retain fluid and have a change in appetite.

LIVING WITH CANCER THERAPY

The experience of being diagnosed with endometrial cancer and undergoing cancer treatment may change the way you feel about your body and will affect your life in many ways. You may experience many or relatively few side effects. Being aware of the possible treatment effects may help you anticipate them and plan ways to cope.

Fatigue

Regardless of the treatment prescribed, you are likely to experience fatigue, frequent medical appointments, and times when you do not feel well enough to take care of tasks at home. You will need to rely on family and friends to help with some of the things you usually do. You may want to consider hiring out for some chores until you feel well enough to manage again. If you know that you will not have support at home, talk frankly with your health care team as early as possible so that alternatives can be explored. Since a nourishing diet is important, be sure to ask for help, if needed, in maintaining healthy meal and snack choices in your home.

Be sure that your blood count is checked to rule out anemia as a treatable cause of fatigue. There are also medications for the relief of fatigue.

Work life

You will probably need to be away from work quite a bit during the first month or two of your treatment. Talk with your supervisors at work and with your health care team to set up a realistic plan for work absences and return to work. Remember to tell your work supervisor that any plan must be flexible because your needs may change as treatment progresses. The Family Medical Leave Act (FMLA) offers certain protections for workers and family members who must be away from work for health reasons.

Facing the world

The effects of cancer and your cancer treatment may alter your appearance. You may appear fatigued, pale, slow moving, and you may have to face temporary mild hair loss. You may feel self-conscious because of these changes. It might help to imagine how you might feel if you saw a friend or sister looking as you do. Remember that many people are loving you rather than judging you as they notice these changes.

Family, friendships and fun

Cancer treatment is not fun — no matter what therapy is prescribed cancer treatment and the usual side effects are no laughing matter. Still, you will have times when you feel well and ready to enjoy life. Talk to your health care team if special events are coming up such as a wedding or graduation. The timing of your treatments may be able to be adjusted so that you feel as well as possible for these special days. Don't hesitate to plan activities that you enjoy. You may have to cancel on occasion or leave a little early, but the good times will help you to find strength for the hard days.

It is often difficult for young children to understand what you are going through. Counselors are available to help you answer questions and to help your children cope. It is also a good idea to ask family and friends to help you keep your children's normal routine.

Driving

Driving is an almost indispensable part of adult life. You should not drive if you are taking medications that cause drowsiness, such as narcotic pain relievers and some nausea medications. Most women can start driving again within a few weeks of surgery and usually women can drive most days during chemotherapy and radiation therapy. Be sure to ask your health care team about driving.

Sexuality and intimacy

Some treatments for endometrial cancer can cause side effects that may change the way you feel about your body or make it difficult to enjoy intimate or sexual relationships. Which side effects you experience depend on your treatment course. You may experience some or none at all. Being aware of the possible side effects may help you anticipate them and learn ways to cope with them.

Possible side effects include:

- ▶ **Hair loss.** A common side effect of chemotherapy, hair loss is usually temporary. Still, it can be difficult to accept. If you experience hair loss, you may choose to wear flattering wigs, scarves, or other headwear.
- ▶ **Vaginal changes.** Some forms of treatment, such as hysterectomy and radiation therapy, may cause dryness, shortening, and narrowing of the vagina. These changes can make sexual activity uncomfortable. Using an over-the-counter vaginal lubricant may help you feel more comfortable. Your treatment team may also recommend a vaginal dilator.
- ▶ **Reduced sexual desire.** The stress and fatigue you may experience during cancer treatment may cause you to lose interest in sex for a period of time.

TIPS FOR COPING

Talk with your treatment team. Your treatment team members can provide advice based on your individual situation, so it is very important that you talk honestly with them. You may want to ask:

- ▶ How will my treatment affect my sexuality?
- ▶ Will these effects be temporary or permanent?
- ▶ Are there other treatment options that might lessen these effects?
- ▶ Do you have suggestions about how I can deal with the effects of treatment on my sexuality?

Communicate with your partner. Having cancer can strain both partners in a relationship. Talking about the sexual and emotional effects cancer has on your relationship can be difficult. But you may find it easier to work through the challenges if you talk through them together. Be prepared to share your own feelings and to listen to what your partner has to say.

Shift your focus to intimacy. Sexual intercourse is only one part of intimacy. You may find that touching, kissing, and cuddling are equally fulfilling.

Be patient with yourself. Understand that a return to a sexual relationship may take time. Your treatment team can tell you if and how long you should wait to have sex after treatment. It may be longer before you feel emotionally ready. Give yourself the time you need.

Keep an open mind. Having an open mind and a sense of humor about ways to improve your sexuality may help you and your partner find what works best for you.

Seek support. There are many resources available to help you deal with any 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 back cover.

Exercise

During treatment you may find that even the stairs to your bedroom are a challenge, even if you have worked hard during your adult life to keep fit. It's discouraging, but normal, to have to reduce or interrupt your fitness routine. If you've had surgery, ask your doctor for specific guidelines about exercise. During chemotherapy or radiation, adjust your exercise according to how you feel.

You should avoid overexerting or dehydrating yourself. Over the weeks and months after you finish cancer treatment you can build back toward your previous level of fitness.

FINAL MESSAGE

As you go through cancer treatment, remember that a return to your full health is your goal. Your treatment team can guide you through this journey. You know what is troubling you, and you know what you need. Give yourself the time you need to heal.

Advance Directives can be helpful in your wishes. We encourage both you and your health care team is available to discuss your wishes.

Nurture hope. It's up to you to face the unknown of cancer treatment.

If you have inner spiritual strength, use it to give you additional strength.

Seek support. There are many people who understand the physical, sexual, or emotional impact of cancer and its treatment. Speak with the impact of cancer on your life. People who are together to share their experiences can provide emotional support. To find a member of your treatment team, remember you are surrounded by love. Remember you are surrounded by love. Remember you are surrounded by love.

TAKE ACTION — TELL A FRIEND!

About 85% of women with endometrial cancer survive this disease. That is because three out of every four women with endometrial cancer are diagnosed at stage I, the earliest stage. These early diagnoses are made possible when women pay attention to symptoms.

Here are the signs and symptoms of endometrial cancer.

- ▶ Vaginal bleeding or spotting after menopause
- ▶ New onset of heavy menstrual periods or bleeding between periods
- ▶ A watery pink or white discharge from the vagina
- ▶ Two or more weeks of persistent pain in the lower abdomen or pelvic area
- ▶ Pain during sexual intercourse

Over 90% of women diagnosed with endometrial cancer say that they experienced abnormal vaginal bleeding prior to their diagnosis. Please see a gynecologist or gynecologic oncologist and ask about an endometrial biopsy if you experience any of these symptoms.

FINAL MESSAGES

As you go through cancer treatment be patient with yourself. Understand that a return to your full and wonderful 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 health care 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 community to give you additional support to face each day and LIVE.

Seek support. There are many resources available to help you deal with the physical, sexual, or emotional issues you may have as 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 below. Remember you are surrounded by a devoted health care 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.cancer.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



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The Elizabeth Gillespie

Fund for Life

dedicated to the early detection of ovarian cancer