



U N D E R S T A N D I N G C e r v i c a l C a n c e r

A WOMAN'S GUIDE



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INTRODUCTION

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

A team of health care 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. To play an active role during your treatment, it helps to learn as much about cervical cancer as possible.

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

CERVICAL CANCER: AN OVERVIEW

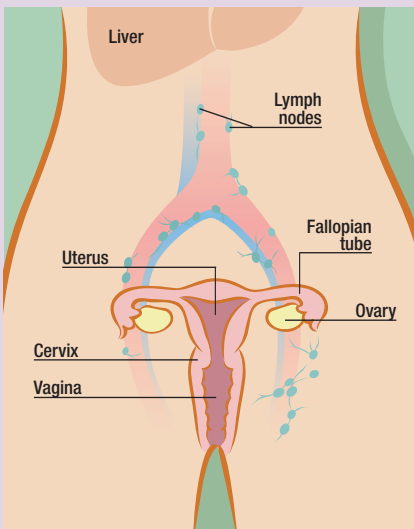
Cancer occurs when cells in an area of the body grow abnormally. Cervical cancer starts in the cervix, the narrow opening at the bottom of the uterus (or womb), also known as the mouth of the womb. The uterus is where a baby grows during pregnancy. The cervix connects the uterus to the vagina, which leads to the outside of a woman's body. These reproductive organs are located in the pelvis, close to the bladder and rectum.

It can take many years for cervical cancer to develop. Normal cells in the cervix tissue may become abnormal (or precancerous) for a number of reasons. These cells can usually be detected by Pap tests. Sometimes these abnormal cells are not detected because screening was not done or they were not detected. When this happens and they are not treated, they may turn into cancer cells.

Cervical cancer is one of just a few cancers caused by a virus. The virus, called human papillomavirus (HPV) can infect a woman's cervix when she has sex. OK — so now we've said it — most cervical cancer is related to a virus which is transmitted through sexual contact. This connection may shock you or make you feel embarrassed. It's important for you to remember that sex is a normal part of adult life. HPV is common in all women who've had sex. Most are just fortunate not to get cancer from the virus. It is not possible to know when or from whom you got HPV, and spending energy on guilt, blame or anger is just not helpful. You will need to focus your energy on getting through your cancer care.

STAGING

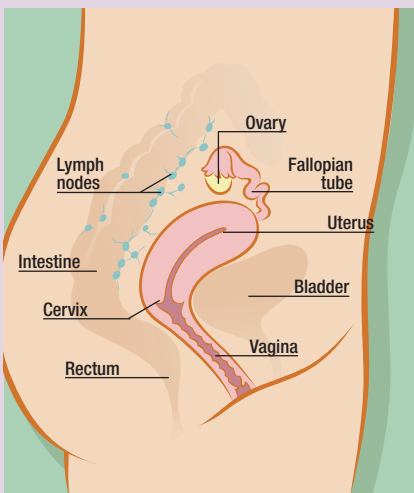
After cervical cancer is diagnosed, your treatment team will do more tests to determine if the cancer has spread. If necessary, further tests, such as X-rays, CT scans or additional biopsies are done to determine how far it has spread. This process is called staging. Staging helps to determine what treatment plan is best for you.



Cervical cancer is grouped into four stages.

Stage I: The cancer is found only in the cervix.

Stage II: The cancer has spread from the cervix to the upper part of the vagina or the tissue around the uterus. It has not spread to the pelvic wall. (The pelvic wall is the muscle and connective tissues that line the insides of the pelvic bones.)



Stage III: The cancer has spread to the lower part of the vagina or to the pelvic wall. It may block the flow of urine to the bladder. Cancer cells may also be found in the lymph nodes in the pelvis.

Stage IV: The cancer has spread to other body parts within or outside of the pelvis. Cancer cells may be found in the bladder, rectum, abdomen, liver, intestines 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 medical and surgical care of reproductive tract cancers like cervical cancer 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 a friend to take notes during your appointments. Your friend can write down questions and answers, remind you of questions you wanted to ask, and help you to remember details of what was said.
- If you don't understand something, ask the treatment team member to explain it again in a different way.

TREATMENT

Cervical cancer may be treated with surgery, radiation therapy or chemotherapy. 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 cervical cancer have side effects. Most side effects can be managed or minimized. Some treatments may affect your sexual function or your ability to have children.

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

For early cervical cancer the most common treatment is surgery. Several types of surgery can be performed but the final choice for you will depend on certain characteristics that your oncologist will consider, especially the stage and size of your cancer.

Cervical conization: Conization means surgical removal of just the cancerous part of the cervix. Conization is an option only for the earliest cancers. This is the preferred treatment for women with very small cancers who wish to preserve fertility.

Vaginal or abdominal hysterectomy: In a vaginal hysterectomy, the uterus and cervix are removed through the vagina. In an abdominal hysterectomy, these organs are removed through an incision on the abdomen.

Radical abdominal hysterectomy: This procedure also requires an abdominal incision. The word radical means that the uterus and the tissue between the uterus and pelvic wall, as well as part of the upper vagina, are removed. Lymph nodes in the pelvis are also removed and examined to determine if the cancer has spread (radical pelvic lymphadenectomy).

In some case, both ovaries and both fallopian tubes must be removed. This procedure is called a bilateral salpingo-oophorectomy.

Radical trachelectomy: This is a newer surgery that is under investigation. The cervix and surrounding tissues are removed but the upper uterus is preserved for future pregnancy. This operation is only available for carefully selected women in a few major medical centers.

Side effects of surgery

Some pain and discomfort are common after surgery. Pain can be controlled with medicine. Tell your treatment team if you are experiencing more than mild pain.

Other early side effects (days to weeks after surgery):

- Nausea
- Discomfort related to tubes, catheters and medical devices
- Difficulty urinating so that a catheter that may stay in your bladder for a few days to weeks is often necessary
- Soreness of the abdomen around the incision
- Cramps and gas pains
- Watery vaginal discharge or bleeding

Later side effects (weeks to months):

- Fatigue
- Difficulty urinating
- Constipation
- Shortening of the vagina

Some things may be done at the time of your surgery to minimize these side effects (such as placement of a temporary drainage catheter in your bladder). Women who have a hysterectomy will stop having periods and will no longer be able to have children. Hormone levels will be the same if the ovaries are left in or may fall to menopausal levels if the ovaries are removed. Hormone therapy to treat menopausal symptoms is usually an option if the ovaries are removed.

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 an effective treatment for early stage cervical cancers. However, in early cervical cancer, it is more commonly used as extra treatment after surgery for patients at highest risk for relapse. Doctors also use radiation to treat larger or higher stage cancers. Your individual need

for radiation therapy will be determined using information from your staging tests, examinations, and from findings at the time of surgery.

Two types of radiation therapy are used to treat cervical cancer. Radiation therapy for cervix cancer is most often given in combination with chemotherapy. When you go home after radiation, you do not need to stay away from family and friends.

- ▶ **External radiation therapy** uses a machine that directs the X-rays toward a precise region of the body. The therapy is usually given daily, Monday through Friday, for about six weeks. Radiation does not hurt and only takes a few minutes. You can be treated at a clinic, hospital, or radiation oncology office and typically you return home each day after treatment.
- ▶ **Internal radiation therapy** (also called brachytherapy) involves placing a small capsule of radioactive material inside the vagina or near the cervix. This procedure can sometimes be performed on an outpatient basis and other times it requires hospitalization for a night or two. Medication is given to alleviate the discomfort from these procedures.

Side effects of radiation

The side effects of radiation therapy depend on the dose used and the part of the body that is being treated. Common side effects for cervix cancer patients are listed below.

Early side effects (occur during treatment):

- ▶ Dry, reddened skin in the treated area
- ▶ Fatigue
- ▶ Anemia
- ▶ Diarrhea and nausea
- ▶ Discomfort when urinating

Most of these side effects are temporary. Not everybody experiences all of these side effects. Be sure to talk with your treatment team members about any side effects you experience. They can help you find ways to manage them.

Late side effects from radiation therapy include:

- Narrowing of the vagina and loss of lubrication
- Urinary frequency
- Diarrhea (radiation colitis)
- Early or sudden menopause (if the ovaries stop working)

Be sure to talk with your health care team about what you can do to reduce your risk of having long-term side effects from the radiation. Some long-term complications, for example narrowing of the vagina, are better prevented than treated once they are severe.

CHEMOTHERAPY

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

The drug or drugs travel through the bloodstream to reach all parts of the body. This is why chemotherapy can be effective in treating cervical cancer that has spread. However, the same drugs that kill cancer cells damage some healthy ones, causing chemotherapy side effects. To limit the damage to healthy cells, chemotherapy is usually given in cycles. Periods of chemotherapy treatment are alternated with rest periods when no chemotherapy is given. Side effects usually still occur, but are manageable.

Side effects of chemotherapy

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
- ▶ Vomiting
- ▶ Loss of appetite
- ▶ Mild hair loss
- ▶ Mouth sores
- ▶ Increased chance of infection
- ▶ Fatigue
- ▶ Bleeding or bruising easily
- ▶ Constipation

LIVING WITH CANCER THERAPY

The experience of being diagnosed with cervical 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.

Intimacy and sexuality

During surgical recovery, radiation and/or chemotherapy treatments, your desire for sexual intercourse may be very low. This is normal for a time, but after treatment couples should work together to find ways to bring sex back into their lives. There is no need to avoid sex during radiation or chemotherapy, so let comfort be your guide. If you feel well enough to have sex, go ahead. After hysterectomy or radical hysterectomy, most surgeons recommend avoiding vaginal intercourse for four to six weeks. You may safely start to have sex again as soon as your surgeon says it's okay. Even when you don't feel well enough to have sex, keep the intimate feelings alive by holding hands, touching, cuddling and kissing. Sexual response (lubrication and orgasm) can be changed after cervical cancer treatment. Talk to your doctor or seek expert help if you or your partner are not happy with your progress toward intimacy after treatment.

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 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.

CERVICAL CANCER RESOURCE LIST

This list was developed by the Gynecologic Cancer Foundation's National Cervical Cancer Public Education Campaign to help women diagnosed with cervical cancer, and their families, find more information about the disease and seek support. The sources in this list are provided for information only and inclusion does not constitute a recommendation.

American Cancer Society

www.cancer.org

1-800-ACS-2345

The American Cancer Society is dedicated to eliminating cancer as a major health problem by saving lives, diminishing suffering and preventing cancer through research, education, advocacy and service. Founded in 1913 and with national headquarters in Atlanta, the Society has 14 regional Divisions and local offices in 3,400 communities, involving millions of volunteers across the United States.

American Social Health Association

www.ashastd.org

919-361-8400

The American Social Health Association is dedicated to improving the health of individuals, families, and communities, with a focus on preventing sexually transmitted diseases and their harmful consequences.

CancerCare

www.cancercare.org

800-813-HOPE(4673)

CancerCare's mission is to help people face the many challenges of a cancer diagnosis. As the largest national nonprofit organization of its kind, CancerCare provides free professional support services including counseling, education, financial assistance, and practical help to people across the country. Our services are available to people of all ages, with all types of cancer and at any stage of the disease.

Centers for Disease Control and Prevention

www.cdc.gov/cancer/nbccedp/index.htm

888-842-6355

The Centers for Disease Control and Prevention (CDC) is recognized as the lead federal agency for protecting the health and safety of people-at home and abroad-providing credible information to enhance health decisions, and promoting health through strong partnerships.

Eyes on the Prize

www.eyesontheprize.org

EyesOnThePrize.org, a nonprofit online support group, provides information and emotional support from the survivors' perspective to women with gynecologic cancers, their families and caregivers. As a support community for living with gynecologic cancer, EyesOnThePrize.org offers survivor stories, answers to questions, resources, discussion about cervical, endometrial, uterine, ovarian, vulvar, gestational and other reproductive cancers. The site includes: warning signs, risks, diagnosis, treatment options and side effects for all gynecologic cancers; links to related sites and opportunity to join private discussion list; database of "on-the-ground" local community GYN cancer support groups.

Gynecologic Cancer Foundation

www.thegcf.org

312-578-1439

The mission of the Gynecologic Cancer Foundation (GCF) is to ensure public awareness of gynecologic cancer prevention, early diagnosis, and proper treatment, as well as to support research and training related to gynecologic cancers. GCF advances this mission by increasing public and private funds that aid in the development and implementation of programs to meet these goals.

National Cancer Institute

www.cancer.gov/cancerinfo/types/cervical/

800-422-6237

The National Cancer Institute (NCI) is a component of the National Institutes of Health, one of eight agencies that compose the Public Health Service in the Department of Health and Human Services. The NCI, established under the National Cancer Act of 1937, is the Federal Government's principal agency for cancer research and training.

National Cervical Cancer Coalition

www.nccc-online.org

800-685-5531

The National Cervical Cancer Coalition (NCCC) is a coalition of women and family members/caregivers battling cervical cancer issues. Involved groups include: women's groups, cytotechnologists, pathologists, laboratories, technology companies, cancer researchers, hospitals, organizations providing cervical cancer screening programs and other related associations.

OncoLink

www.oncolink.com

215-349-8895

OncoLink was founded in 1994 by University of Pennsylvania cancer specialists with a mission to help cancer patients, families, health care professionals and the general public receive accurate cancer-related information at no charge. OncoLink provides comprehensive information about specific types of cancer, updates on cancer treatments and news about research advances.

Society of Gynecologic Oncologists

www.sgo.org

312-644-6610

The Society of Gynecologic Oncologists (SGO) formed the Gynecologic Cancer Foundation in 1991 and is a national medical specialty organization of physicians who are trained in the comprehensive management of women with malignancies of the reproductive tract. Its purpose is to improve the care of women with gynecologic cancer by encouraging research, disseminating knowledge which will raise the standards of practice in the prevention and treatment of gynecologic malignancies and cooperating with other organizations interested in women's health care, oncology and related fields.

The Agency for Healthcare Research and Quality

www.ahrq.gov

301-427-1364

The Agency for Healthcare Research and Quality's mission is to improve the quality, safety, efficiency, and effectiveness of health care for all Americans. Specific information about cervical cancer can be found under "Preventive Services," "Women's Health," and "Consumers & Patients" sections of the Web site.

The American Society for Colposcopy and Cervical Pathology

www.asccp.org

301-733-3640

Established in 1964, the American Society for Colposcopy and Cervical Pathology (ASCCP) is the organization of health care professionals committed to improving health through the study, prevention, diagnosis, and management of lower genital tract disorders.

The Witness Project of Harlem

www.witnessprojectharlem.org

212-659-5517

The Witness Project of Harlem is a breast and cervical cancer education project focusing on African-American women.

U.S. Food and Drug Administration's Office of Women's Health

www.fda.gov/womens/

1-800-994-WOMAN

The mission of the U.S. Food and Drug Administration's Office of Women's Health is to serve as a champion for women's health both within and outside the agency.

Women's Cancer Network

www.wcn.org

312-578-1439

The WCN is an interactive Web site dedicated to informing women about gynecologic cancers. Its goal is to assist women who have developed cancer, as well as their families, to understand more about the disease, learn about treatment options, and gain access to new or experimental therapies. The site was developed by the Gynecologic Cancer Foundation and CancerSource. Specific information about cervical cancer can be found by clicking on "Cancer Info" from the main menu and selecting the link to "cervical cancer."



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National Cervical Cancer
public education campaign

GCF is the lead partner of the National Cervical Cancer Public Education Campaign. For more information about the Campaign, please visit www.cervicalcancercampaign.org or call 1.866.280.6605.



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