



Foundation
for Women's Cancer



CERVICAL CANCER

Your Guide

RESEARCH · AWARENESS · OUTREACH · EDUCATION



Introduction

You and your family have learned of 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 many unanswered questions, decisions to be made, and so much information to understand. It can be helpful to have friends and family with you when discussing your diagnosis and treatment.

A team of health care professionals will work with you and your family 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 as possible about cervical cancer.

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. Also, it will identify the different types of treatments for cervical cancer. Hopefully, this information will 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 is a cancer that begins in the cervix, the part of the uterus or womb that opens into the vagina. It is the part of the uterus that dilates and opens fully to allow a baby to pass into the birth canal. The normal cervix has two main types of cells: squamous (or flat) cells, which protect the outside of the cervix, and glandular cells which are mostly inside the cervix, and produce the fluid and mucus commonly seen during ovulation.

Cervical cancer is caused by abnormal changes in either of these cell types in the cervix, and is the only gynecologic cancer that can be prevented by regular screening and preventive vaccination.

Prevention, screening, early detection

Nearly all cervical cancers are caused by persistent infection with a high-risk type of human papillomavirus (HPV). The HPV vaccine is a cancer prevention vaccine that can prevent many HPV related cancers including cervical cancer. Vaccinating boys and girls ideally at age 11-12 yo before they become sexually active leads to the greatest prevention of precancer and cancer. All young people age 9-26 are recommended to get the cancer preventing HPV Vaccine. The HPV vaccine is available for men and women up to age 45 years of age.

Even if vaccinated, regular Pap smears and HPV tests are the most important way to prevent cervical cancer or find it when it is earlier and can best be treated. Follow up after abnormal testing and knowing your results are an important way you can advocate for yourself.

Symptoms

Cervical precancers usually have no symptoms. That is why it is important to have a Pap and/or HPV test. A person may not have any symptoms until the cells turn into cancer and invade the deepest parts of the cervix or other pelvic organs.

These symptoms include:

- Vaginal discharge
- Abnormal vaginal bleeding
- Vaginal odor
- Pain

These symptoms may be caused by cancer or by other health problems. It is important for a woman to see her doctor if she is having any of these symptoms.

Cervical cancer usually affects patients between the ages of 30 and 55 but remember it can affect any person with cervix who has not been screened in a long time or has symptoms. Be sure you are up to date on your testing and encourage others do the same.

Medical evaluation

When a woman experiences concerning symptoms, a pelvic exam, including a rectovaginal exam, and a general physical should be performed. If the exam is abnormal, the woman might be advised to undergo extra testing such as a more specific HPV test, a colposcopy (observing the cervix through a magnifying scope), and a biopsy, depending on the results of the colposcopy.

If cervical cancer is suspected or diagnosed, it is important to seek care first from a gynecologic oncologist.

To find a gynecologic oncologist in your area, log onto the Foundation for Women's Cancer website (foundationforwomenscancer.org) and enter your zip code.



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 following health care professionals:

Gynecologic oncologists are board-certified obstetrician-gynecologists who have an additional three to four years of specialized training in treating gynecologic cancer from an American Board of Obstetrics and Gynecology-approved fellowship program. A gynecologic oncologist can manage your care from diagnosis to completion of treatment.

You also may be treated by:

Medical oncologists who specialize in using drug therapy (chemotherapy) to treat cancer.

Radiation oncologists who specialize in using radiation therapy to treat cancer.

Oncology nurses who specialize 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 workers who are professionally trained in counseling and practical assistance, community support programs, home care, transportation, medical assistance, insurance, and entitlement programs. They are very helpful advocates, especially when you are first diagnosed and unsure about what to do next.

Patient navigators who educate patients about the disease and serves as an advocate on behalf of the patient and her caregivers throughout the cancer treatment.

Nutritionists or registered dietitians who help you maintain or initiate healthy eating habits. This is important in the recovery process. These professionals can help you overcome potential side effects of treatment such as poor appetite, nausea, or mouth sores. It is important to note that natural remedies and supplements should be taken only under the supervision of a naturopathic physician in consultation with your gynecologic oncologist.

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 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 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.

When cervical cancer is diagnosed, it is vital to determine if the cancer has spread. Your treatment team may do more tests to determine this. Additionally, specific procedures during surgery may 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.

Staging your cancer will be categorized into Stage I, II, III, or IV, illustrated on the following page. If you are able to have surgery, the results of the surgery may help to determine the stage. If surgery is not planned because of the size of the tumor or location, the stage may be determined by radiologic tests such as CT, PET-CT or MRI. The stage of the cancer will help your team decide the best treatment plan tailored for you. The cancer will also be assigned a grade. Grade refers to how abnormal the cells appear under a microscope. Low grade tumors, also called grade 1, have features that resemble normal cervical cells. In contrast, in high grade tumors (grade 3) the microscopic appearance is greatly altered from normal.

Once diagnosed with cervical cancer, your medical team may recommend imaging (radiology tests) such MRI, CAT (CT) scans or PET scans to help establish exactly where the cancer is located and design the best plan.

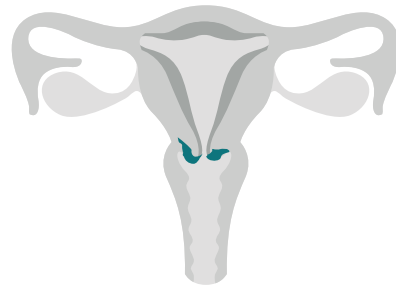
It is important that your surgery be performed by a gynecologic oncologist, a physician with special training in the care of women's reproductive cancers. Studies show that patients treated by gynecologic oncologists at high-volume centers have improved outcomes.

Cancer Staging

Cervical cancer stages

Stage I

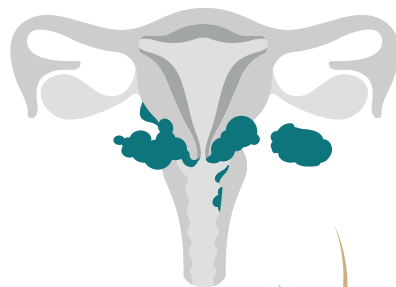
The cancer is found only in the cervix.



Stage II

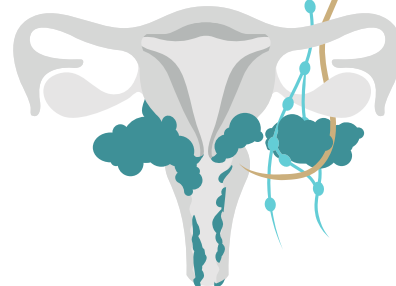
The cancer has spread from the cervix to the upper part of the vagina or the tissue around the uterus.

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.) Cancer cells may also be found in the lymph nodes in the pelvis.



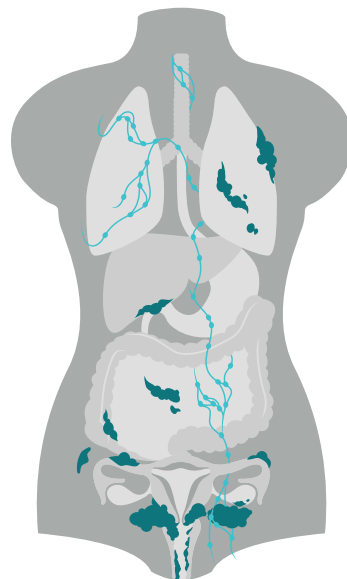
Stage III

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 the pelvis. Cancer cells may be found in the bladder, rectum, abdomen, liver, intestines, or lungs.





Treatment types & side effects

Cervical cancer may be treated with surgery, radiation therapy, and/or chemotherapy. Depending on a number of factors, your treatment team may recommend using a combination of treatments to treat your cancer.

Understanding the goals of treatment

As you begin your treatment, make sure that you understand what to expect. Is this for cure? What are the chances of cure? If there is no cure, will the treatment

make me live better or longer? It is very important to understand the truth about what to expect from the treatment — and what are the potential costs of side effects, expenses, etc. — so that you can make the best decisions for yourself and the life you want to lead. Treatments for cervical cancer have side effects. Most

side effects can be managed or minimized. Common side effects can affect bowel or bladder function, sexual function or the ability to have children so getting the information you need from your treatment team should be a priority.

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 that you experience.

Surgery

Surgery is the most common treatment for early cervical cancer, although radiation can also be used and typically works equally as well. Several types of surgery can be performed, but the final choice for you will depend on several factors that your gynecologic oncologist will consider, especially the stage and size of your cancer as well as your age, general health and fertility sparing options.

Cervical conization

Conization means surgical removal of just the cancerous (or precancerous in many cases) part of the cervix. Conization is an option only for the earliest cancers, the ones that are microscopic. This is the preferred treatment for women with very small cancers who wish to preserve fertility.

Simple hysterectomy

In a simple abdominal hysterectomy, the uterus and cervix are removed through an incision on the abdomen. In the less common vaginal hysterectomy, these organs are removed through the vagina. These types of hysterectomy are reserved also for very early cancers in patients who do not wish to preserve their uterus.

Radical trachelectomy

In this surgery, your cervix and surrounding tissues are removed, but the upper uterus is preserved for future pregnancy. This operation is only available for carefully selected women and is dependent on several factors such as age, fertility, tumor size, imaging or tumor type.

Radical hysterectomy

This is a more complex surgery performed to remove the uterus/cervix and additional tissue. This is most often performed via an open abdominal incision. The word radical means that the uterus and the additional tissue between the uterus and pelvic wall, as well as part of the upper vagina, are removed.

While there are many approaches to the type of surgery, open (abdominal) or minimally invasive (laparoscopic or robotic), newer data suggest outcomes may be better with a traditional abdominal incision. While some controversy exists for select clinical situations, it is important to understand your surgery approach and speak to your surgeon about risks, benefits and expectations.

Lymph node evaluation

During these surgeries, lymph nodes in the pelvis are also removed and examined to determine if the cancer has spread. A full lymph node dissection (pelvic lymphadenectomy) means removal of lymph nodes in a standard area along the blood vessels. Locating and removing only select lymph nodes that are located using a dye technique is called sentinel lymph node mapping and can minimize side effects of lymph node removal such as lymphedema (swelling in legs).

Removal of tubes and ovaries

In some cases, both ovaries and both fallopian tubes must be removed. This procedure is called a bilateral salpingo-oophorectomy. But often for younger women, the ovaries may remain in place. Talking to your surgeon about the risks, benefits of ovarian removal is an important part of understanding your surgical plan.



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):

- Soreness of the abdomen around the incision
- Nausea or decreased appetite
- Difficulty urinating so that a Foley catheter that may stay in your bladder for a few days to weeks may be necessary
- Cramps and gas pains
- Small amount of discharge or bleeding
- Fatigue

Later side effects

- Difficulty urinating
- Constipation
- Shortening of the vagina depending on the extent of surgery

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 remain 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 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 recurrence of their cancer (such as when the tumor might have spread beyond the cervix). Radiation along with chemotherapy is most commonly used to treat larger or higher-stage cancers where it is more effective than surgery. Your need for radiation therapy will be determined using information from your staging tests, examinations, and surgery (if an operation was performed based on findings at the time of your evaluation).

Two types of radiation therapy are used to treat cervical cancer. Radiation therapy for cervical cancer is most often given in combination with chemotherapy.

External radiation therapy uses a machine that directs the radiation toward a precise region of the body. The therapy is usually given daily, Monday through Friday, for about six weeks. Radiation does not hurt during the treatment and only takes a few minutes each day. 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 requires hospitalization for a night or two. Medication is given to alleviate the discomfort from these procedures. During the time the radiation capsules are in, your family may be allowed only limited time next to you, but the radiation capsules are removed prior to going home.

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 for cervix cancer patients are listed below.

Early side effects

(occurring 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 that you experience. They can help you find ways to manage them.

Later side effects:

- Narrowing of the vagina and loss of lubrication
- Urinary frequency (radiation cystitis)
- Diarrhea (radiation colitis)
- Early or sudden menopause (if the ovaries stop working)
- Skin thickening and irritation
- Pelvic pain
- Lymphedema (swelling of legs)

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 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 cervical cancer that has spread beyond the cervix. However, the same drugs that kill cancer cells may also damage healthy cells. To limit the damage to healthy cells, chemotherapy is usually given in cycles. Periods of chemotherapy are alternated with rest periods, during which no chemotherapy is given. Side effects usually still occur, but are manageable. Immunotherapy, including drugs that are delivered through the IV, may be an additional way that cervical cancer that has recurred can be treated.

Side effects of chemotherapy

Side effects vary with the type of chemotherapy drugs used and the number of drugs used. In addition, chemotherapy may be used for initial treatment or if there is a recurrence of the cancer. Each person responds to chemotherapy differently. Some people may have very few side effects while others experience several. Most side effects are temporary. Understanding which specific chemotherapy you will be on and the specific side effects is important. General side effects of chemotherapy may include:

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

Importance of participation in clinical trials

There are many ongoing clinical trials studying new and better ways to treat cervical cancer. Many treatment options are available today because women diagnosed with a gynecologic cancer were willing to participate in prior clinical trials.

Clinical trials are designed to test some of the newest and most promising treatments for cervical cancer. The Foundation for Women's Cancer partners with NRG Oncology (formerly Gynecologic Oncology Group), part of the only National Cancer Institute cooperative group working exclusively on gynecologic cancer clinical trials, and others to make information about current clinical trials available. All patients regardless of race, ethnicity, language spoken, socio-economic status or age are potentially eligible for trials and trials are better when there is more diverse participation.

For more information about clinical trials available for enrollment, visit www.clinicaltrials.gov.



Living with cancer therapy

The experience of being diagnosed with a gynecologic cancer and undergoing cancer treatment may change the way you feel about your body, and it 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 someone for help with 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.

Facing the world

The effects of cancer and your cancer treatment may alter your appearance. You may appear fatigued, pale, and slow-moving and you may have to face temporary 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.

Work accommodations

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.

Family, friendships, and fun

No matter what type of treatment you have, you may experience side effects that could affect how you feel about joining in social events with friends and family. 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

For many people, 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 patients can start driving again within a few weeks of surgery, and usually patients can drive most days during chemotherapy and radiation therapy. Be sure to ask your health care team about driving.



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 therapy, 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.



Sexuality & Intimacy

Some treatments for cervical 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 that 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.

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 head wear.

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. They 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?
- 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?

Report your symptoms to your medical team and seek care for sexual function concerns.

Do not be afraid to mention any concerns about sexual function with your medical care team. Sexuality is an important part of quality of life for many patients and should not be ignored even your cancer is in control. Physical therapy targeting the pelvic floor and sexual function, therapy including couples therapy, and medications including hormonal and non-hormonal options can help with symptoms.

Communicate with your partner. 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 about them. 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.



Hopeful 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.

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 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 on the next page. Remember, you are surrounded by a devoted health care team, so let us be at your side.

Advance medical 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.

Facts to share

- Most cases of cervical cancer are now preventable.
- Vaccinating young children before they become sexually active can prevent cervical precancer and cancer.
- Regular Pap tests and HPV testing at recommended intervals are equally important in preventing cervical cancer.

Symptoms

- Bleeding after intercourse
- Excessive discharge and abnormal bleeding between periods
- Vaginal odor
- Pain

These symptoms may be caused by cancer or by other health problems. It is important for a woman to see her doctor if she is having any of these symptoms. Most women will have no symptoms, so getting vaccinations and regular Pap tests plus HPV tests when recommended is key to preventing cervical cancer.

Risk factors

- Almost all cervical cancer is caused by a persistent infection with the human papillomavirus, or HPV.
- Cervical cancer usually affects women between 30 and 50, but younger women also are at risk.
- Smoking weakens the immune system and a weakened immune system can lead to persistent HPV infection.

Risk reduction

- Get Pap tests and HPV tests regularly as recommended by your provider, know your results and ask questions about your follow up plan.
- Get the HPV vaccine and recommend the HPV vaccine to others including preteens for cancer prevention in the future.
- The HPV vaccine can help prevent precancer and cervical, vulvar, vaginal, anal, oropharyngeal and other head and neck cancers caused by certain high risk human papillomavirus (HPV) types. Boys and girls should be vaccinated as pre-teens or between age 9-26 years old. The HPV vaccine is also available for men and women up to age 45.

If your test results are positive for cervical precancer or cancer, seek care from a gynecologic oncologist.

How you can help

- Raise awareness about gynecologic cancers.
- Donate to the Foundation for Women's Cancer online.
- Host your own fundraising event or partner with the Foundation.
- Give a Matching Gift through your employer to the Foundation.
- Give gifts of stock or securities to the Foundation.
- Designate a planned gift to the Foundation.

The Foundation for Women's Cancer offers many resources for patients, advocates and the general public, including Survivor Courses around the U.S., webinars and an online education series.

To make a gift or for additional information, please email the Foundation at info@foundationforwomenscancer.org or call 312.578.1439.

Donate & learn more

foundationforwomenscancer.org



The Foundation for Women's Cancer (FWC) is a 501(c)3 nonprofit organization dedicated to increasing research, education and awareness about gynecologic cancer risk, prevention, early detection and optimal treatment.

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