



Foundation
for Women's Cancer



VULVAR AND VAGINAL CANCERS

Your Guide

RESEARCH · AWARENESS · OUTREACH · EDUCATION



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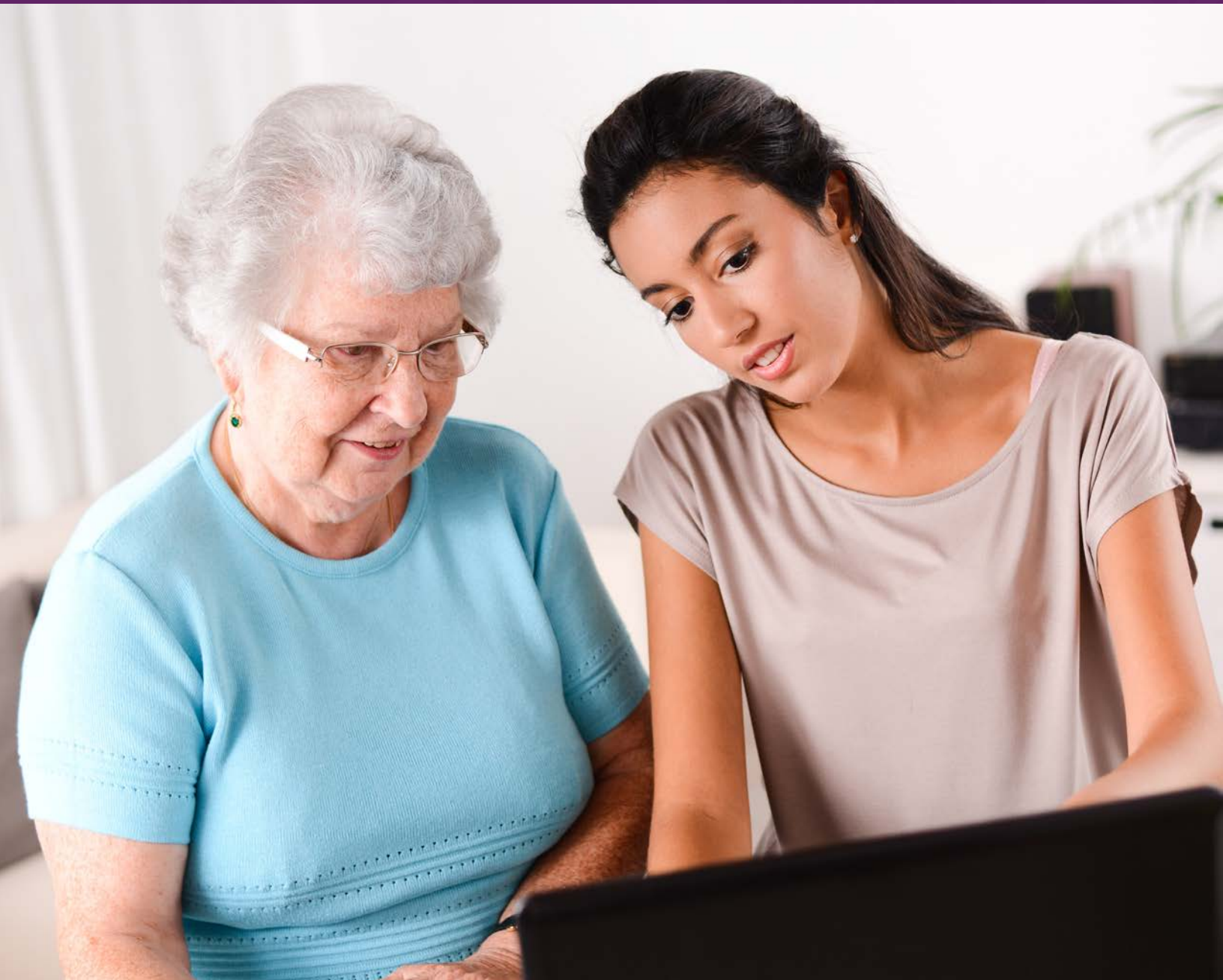


Introduction

A new diagnosis of vulvar or vaginal cancer can feel overwhelming for you and your family and loved ones. Many patients experience an avalanche of questions, decisions, uncertainty or sometimes a sense of de-personalization from the diagnosis as well as the amount of new information being dispensed. A team of health care professionals will work with you and your family throughout the treatment and surveillance process, and they all welcome and understand any questions you or your loved ones may have. It can be helpful to have friends or family with you when discussing your diagnosis and treatment, both for a different perspective as well as to help keep track of the information. Everyone on the team 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 your cancer.

This booklet will take you through the basics of what you need to know about vaginal or vulvar 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 this cancer. Hopefully, this information will help prepare you to talk with your treatment team and to feel more confident about your treatment plan.



Vulvar cancer: Overview

Vulvar cancer begins in the vulva, which is the external genitalia that comprises of the inner and outer labia ("lips"), clitoris, urethra where urine exits, opening of the vagina and its glands, as well as the area of skin between the vagina and anus. It is a rare cancer that can be associated with smoking, human papillomavirus (HPV) infections, as well as conditions of the vulva associated with chronic irritation and inflammation.

Vulvar cancer symptoms

Protection from HPV infection, including HPV vaccination, reduces the risk of vulvar cancer. Examination of the vulva for changes by a woman at home or by her gynecologist during her annual pelvic examination can lead to the detection of preinvasive disease or early vulvar cancer. Suspicious or unexplained changes on the vulva should be biopsied.

Symptoms or signs of pre-cancer and cancer include:

- Chronic itching (more than 1-2 weeks)
- Skin that appears different than usual — different colors (red, pink, black, white), as well as shades (either lighter or darker)
- A bump or lump, which could be red, pink or white, and could have a wart-like or raw surface
- Pain or burning
- Bleeding or discharge not related to the normal menstrual period
- Ulcer or open sore (especially if it lasts for a month or more)
- Cauliflower-like growths



Vulvar cancer staging

In general, cancers are divided into stages, which are categories or stages that denote how far the cancer cells have spread as well as to estimate risk of recurrence. This is found on imaging, surgery, and/or biopsies, and is not the same as grade of cancer, which is how aggressive the cancer cells appear under the microscope.

Vulvar cancer stages

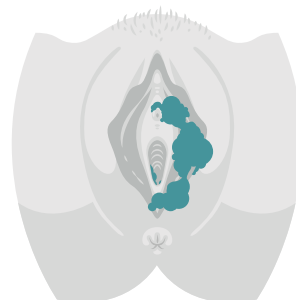
Stage I

The cancer is confined to the vulva or perineum— the area between the anus and the vulva.



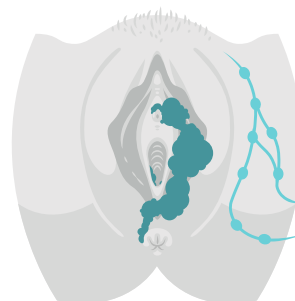
Stage II

The cancer has spread to the urethra, anus or vagina.



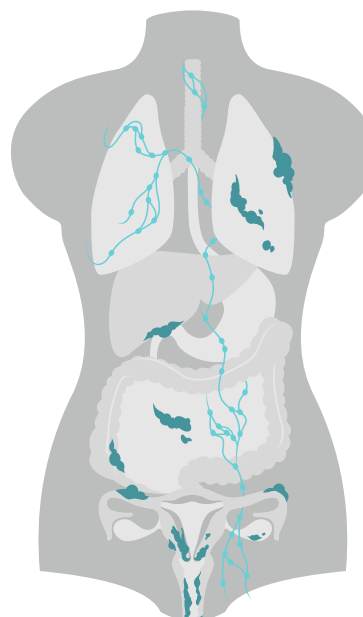
Stage III

The cancer has spread to the lymph nodes.



Stage IV

The cancer has spread further away from the vulva into other parts of the body.



Vulvar cancer treatment and side effects

Surgery

Surgical resection (removal) is often indicated for patients with vulvar cancer—with additional therapy such as radiation or chemotherapy administered based on the stage.

There are several surgical operations to treat vulvar cancer:

- Removal of the cancer and a margin of healthy tissue (excision): cutting out the cancer and at least 3/4 inch (2 centimeters) of the normal tissue (“margin”) all the way around it.
- Removal of a portion of the vulva (partial vulvectomy): removing the superficial portion of the vulva.
- Removal of more of the vulva (radical vulvectomy): removing the superficial and deep portions of the vulva. This may involve removal of the portions of the vulvar close the tumor or possibly the entire vulva, including the clitoris and perineum.
- Removal of lymph nodes (inguinofemoral lymphadenectomy): removing the lymph nodes in the groin that receives lymphatic fluid flow from the vulva. This may be done with the same incision as a radical vulvectomy or via separate incisions.
- Sentinel lymph node biopsy (SLNB): this is a relatively new procedure that involves identifying and removing the lymph node(s) into which the channels near the tumor drains. Removing these select lymph nodes, rather than all of the lymph nodes in the groin, decreases risk or severity of lymphedema, seroma and other complications associated with full lymphadenectomy. If the cancer has not spread to these lymph node(s), it is unlikely to have spread to other lymph nodes.

Depending on the extent of your surgery, reconstructive surgery may be recommended. This is something to discuss with your treatment team if you have undergone a partial or radical vulvectomy.

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 pain. Other possible side effects are:

- Nausea and vomiting
- Infection or fever
- Wound problems
- Anemia
- Swelling caused by lymphedema, usually in the legs
- Blood clots (in the legs, lungs, heart — i.e., heart attack or angina, or brain — i.e., stroke)
- Difficulty urinating or constipation
- Pain (tingling or shock-like sensation) down the legs and or weakness of the legs

Most of these side effects are temporary. 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.

Radiation therapy

Radiation therapy (also called radiotherapy) use high-energy x-rays, or other types of radiation, to kill cancer cells or stop them from growing. Radiation is frequently used for more advanced stages of the disease (Stage II-IVA).

For women being treated for vulvar cancer, the radiation can be delivered in several ways.

- External radiation: uses a machine that directs the radiation toward the entire abdomen or just the pelvis, depending on the location of the cancer. This is usually done every weekday for a few minutes and it should feel similar to getting an x-ray or CT scan.
- Internal radiation (also called brachytherapy): involves placing radioactive beads in the vagina, vulva or surrounding tissue for a specified period of time.

- Proton beam: Proton therapy, also called proton beam therapy, uses protons rather than x-rays to treat cancer.

The extent of the cancer dictates which, or whether, both of these delivery systems are used and in what order.

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:

- Anemia
- Blood in urine or stool
- Diarrhea
- Dry, reddened skin in the treated area
- Discomfort when urinating
- Fatigue
- Narrowing of the vagina
- Pain with intercourse

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

Chemotherapy

Chemotherapy are drugs used to kill cancer cells.

Chemotherapy is usually injected into a vein, but sometimes can be given as a pill. Chemotherapy may be recommended for some women with advanced vulvar cancer.

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

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.





Vaginal cancer: Overview

Vaginal cancer begins in the vagina, the canal that between the outer genitalia (the vulva, including the “lips” and urethra where urine exits) to the uterus. Most of these cancers are on the surface (squamous epithelium) of the vagina and usually affect women between 50-70 years old. Primary vaginal cancer is one of the rarest gynecologic cancers as oftentimes cancer cells found in the vagina originate from uterus, vulva or other organs.

Because many vaginal cancers are associated with the human papillomavirus (HPV) types 16 and 18, vaginal cancer can be prevented by the HPV vaccines which can also prevent cervical cancer.



Types of vaginal cancer

There are four types of vaginal cancer, depending on where the cancer began.

- Vaginal squamous cell carcinoma is the most common type and refers to the thin, flat cells that line the surface of the vagina.
- Vaginal adenocarcinoma begins in the glandular cells on the surface of the vagina that secrete fluid.
- Vaginal melanoma develops from the pigment-producing cells of the vagina.
- Vaginal sarcoma develops in the connective tissue or muscle cells underlying vaginal walls.

Vaginal cancer symptoms

Vaginal cancer, especially at the precancerous and early stages, may not cause any symptoms, so routine examination of the vagina and biopsy if necessary are key for diagnosis.

Common signs for more advanced vaginal cancer include:

- Unusual vaginal bleeding (i.e., between menses, after intercourse, new postmenopausal bleeding)
- Pain (vaginal, vulvar, lower abdominal/pelvic, back or flank)
- Problems with urination or bowel movements
- Watery vaginal discharge
- Lump or mass in the vagina

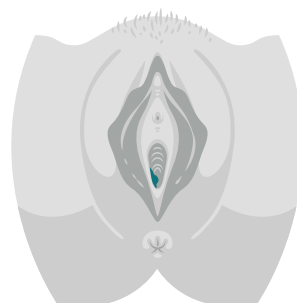
Vaginal cancer staging

In general, cancers are divided into stages, which are categories that denote how far the cancer cells have spread as well as to estimate risk of recurrence. This is found on imaging, surgery, and/ or biopsies, and is not the same as grade of cancer, which is how aggressive the cancer cells appear under the microscope.

Vaginal cancer stages

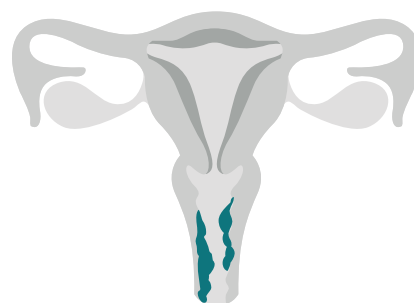
Stage I

The cancer is found only in the vaginal wall.



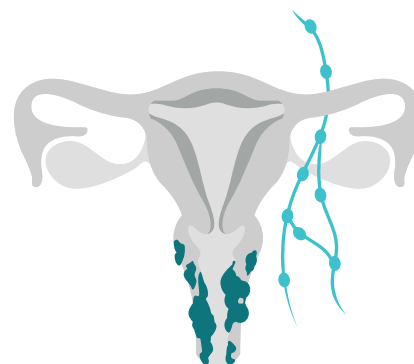
Stage II

The cancer has spread to the tissues underlying or directly next to the vagina.



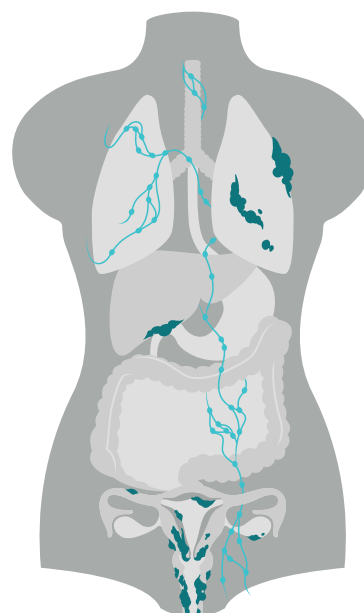
Stage III

The cancer has spread to the lymph nodes or the walls of the pelvis.



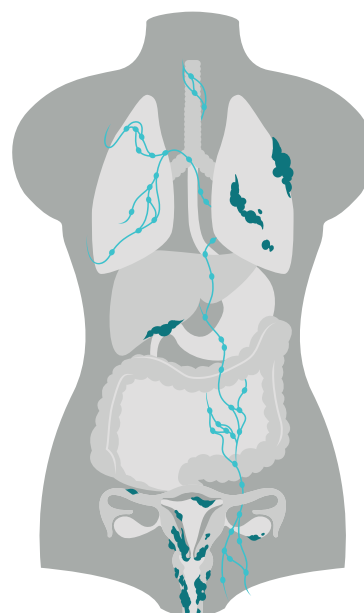
Stage IVA

The cancer also has spread to the bladder, rectum or pelvis.



Stage IVB

The cancer has spread beyond the vagina to areas like the lungs.





Vaginal cancer treatment & side effects

Surgery

Surgery is used primarily for early-stage vaginal cancer that is limited to the vagina or, in select cases, nearby tissue, and may be followed by radiation to ensure sterilization of the pelvis from cancer cells. Large tumors present a challenge since so many important organs are located in the pelvis.

There are several operations to treat vaginal cancer:

- Removal of small tumors or lesions: Cancer only on the surface of the vagina is removed along with a small part of surrounding healthy tissue to ensure that all of the cancer cells have been removed.
- Removal of the vagina (vaginectomy): Removing part of your vagina (partial vaginectomy) or your vagina and its underlying tissues (radical vaginectomy) may be necessary to remove all of the cancer. Depending on the extent of the cancer (see previous section on staging), it may be necessary to perform a hysterectomy (removal of the uterus and ovaries) and nearby lymph nodes at the same time.
- Removal of the majority of the pelvic organs (pelvic exenteration): this may involve removal of the urethra/bladder/distal ureters and/or anus/rectum. Exenteration is used if the cancer has spread locally or if vaginal cancer recurs after radiation.

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 pain. Other possible side effects are:

- Nausea and vomiting
- Infection or fever
- Wound problems
- Anemia
- Swelling caused by lymphedema, usually in the legs
- Blood clots (in the legs, lungs, heart— i.e., heart attack or angina, or brain — i.e., stroke)
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- Diarrhea
- Dry, reddened skin in the treated area
- Discomfort when urinating
- Fatigue
- Narrowing of the vagina
- Pain with intercourse

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

Chemotherapy

Chemotherapy are drugs used to kill cancer cells.

Chemotherapy usually injected into a vein, but sometimes can be given as a pill. At the present time, it is not known if chemotherapy is effective for women with vaginal cancer.

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

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.



Medical evaluation & diagnosis

If vaginal or vulvar cancer is suspected or diagnosed, it is important to seek care first from a gynecologic oncologist — medical doctors with specialized training in treating gynecologic cancers who can manage your care from diagnosis to completion of treatment. Use our [Seek a Specialist](#) tool to find a gynecologic oncologist in your area.

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

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.

Importance of participation in clinical trials

Many treatment options are available today because patients 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 cancer. Please be advised that a clinical trial might be harder to find with rare diseases such as vulvar and vaginal cancers. For more information about clinical trials available for enrollment, visit www.clinicaltrials.gov.

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.

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.



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 gynecologic 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.

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?

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 **vaginal and vulvar cancers** are now preventable.

Vaccinating children against HPV before they become sexually active helps reduce the risk of these cancers.

Regular Pap tests and HPV testing at recommended intervals are equally important in preventing vaginal and vulvar cancers.

Vaginal cancer symptoms

- Unusual vaginal bleeding
- Pain
- Problems with urination or bowel movements
- Watery vaginal discharge
- Lump or mass in the vagina

Vulvar cancer symptoms

- Itching that will not go away
- Skin that appears lighter or darker than usual; it can be red or pink
- A bump or lump, which could be red, pink or white, and could have a wart-like or raw surface
- Pain or burning
- Bleeding or discharge not related to the normal menstrual period
- Open sore (especially if it lasts for a month or more)
- Cauliflower-like growths similar to genital warts
- Ulcer in the genital area

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 vaginal or vulvar cancer.

Risk factors

- Almost all vaginal and vulvar cancers are caused by a persistent infection with the human papillomavirus, or HPV.
- Smoking weakens the immune system and a weakened immune system can lead to persistent HPV infection.

Risk reduction

- Get vaccinated before you become sexually active.
- Have your children vaccinated for HPV starting at age nine.
- Get Pap tests and HPV tests at the intervals recommended by your health care provider.

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



How you can help

Raise awareness about gyn 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.

foundationforwomencancer.org
info@foundationforwomenscancer.org
phone 312.578.1439
fax 312.235.4059

Foundation for Women's Cancer
230 W. Monroe, Suite 710
Chicago, IL 60606-4703

 /foundationforwomenscancer

 @GYNCancer

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