PATIENT & CAREGIVER EDUCATION

About Vulvar Cancer

This information explains vulvar cancer, including symptoms, diagnosis, and treatments.

You do not need to read all of this information at once. It's meant for you to use over time. It may help to read some sections before you talk with your healthcare provider. Some sections may give you a better idea of what to ask them. Other sections may help you remember what your healthcare provider has told you.

About your vulva

Vulva is another name for your external sex organs, or genitals (see Figure 1). Your vulva includes:

- The labia minora (inner lips of your labia).
- The labia majora (outer lips of your labia).
- Your clitoris.
- The opening of your vagina.
- Your vaginal glands, which are in your perineum (area between your vulva and anus).

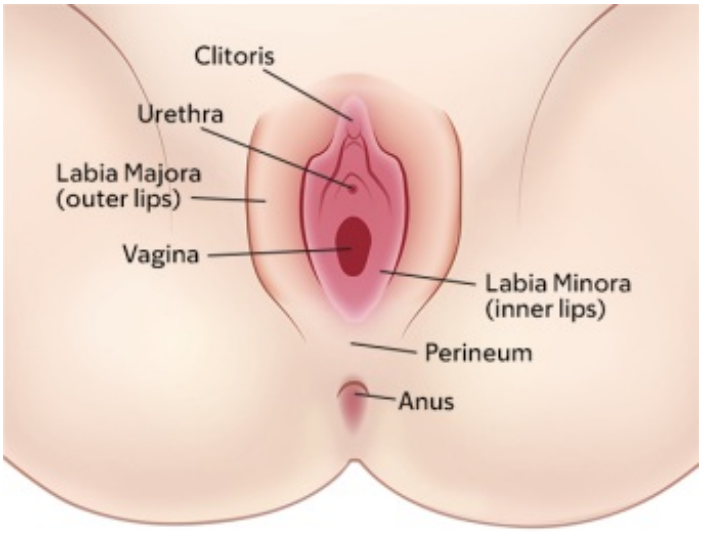


Figure 1. Your vulva

What is vulvar cancer?

Vulvar cancer is a rare form of cancer. It can be in any area of your vulva but is usually in the outer lips of your labia.

Vulvar cancer usually starts as abnormal cells and develops slowly over many years. These abnormal cells are precancerous. They can grow on your vulvar skin for a long time. Precancerous means that these cells aren't cancer, but they may grow into cancer if they aren't treated.

Groups of abnormal cells are called dysplasia or vulvar intraepithelial neoplasia (VUL-ver IN-truh-eh-pih-THEE-lee-ul NEE-oh-PLAY-zhuh).

Causes of vulvar cancer

About half of all vulvar cancers are caused by an infection with certain types of human papillomavirus (HPV). Vaccines that protect against these types of HPV may lower your risk of getting vulvar cancer. Talk with your healthcare provider for more information about HPV vaccines and whether you can get them at MSK.

How to prevent vulvar cancer

Have regular exams to help your healthcare provider notice abnormal cells early. This makes them easier to treat. Treating abnormal cells can keep them from turning into vulvar cancer.

Signs and symptoms of vulvar cancer

Vulvar cancer often doesn't cause symptoms right away. If you have any of these symptoms, do not ignore them.

Use a mirror to examine your vulva once a month. Ask your nurse to show you how to do this. If you see any of the things below, tell your healthcare provider.

- A lump, thickening or ulcer (sore) on your vulva.
- A patch of skin that has a different texture or color than the rest of your skin.
- A change in the way a mole looks.
- Wart-like growths.
- Itching or burning that does not go away with treatment.
- Bleeding or discharge not related to menstruation (periods).
- Tenderness or pain.
- Pain during intercourse (sexual activity) or urination.
- Unusual odor (smell).

These symptoms may be signs of vulvar cancer, or they may be caused by another condition. Your healthcare provider will talk with you and do tests to learn more.

How to diagnose vulvar cancer

There are no screening tests for vulvar cancer. To diagnose vulvar cancer, your healthcare provider will ask about your medical history and do a physical exam. Talk with your healthcare provider about how often you should do this. They may also do other medical exams and tests, such as a pelvic exam, vulvar

biopsy, or imaging scans.

Pelvic exam

During a pelvic exam, your healthcare provider will examine your vagina, cervix, uterus, fallopian tubes, ovaries, and rectum. They will wear gloves and use lubricating gel to put 1 finger into your vagina. They will place their other hand over your lower abdomen (belly) at the same time. This will let them feel the size, shape, and position of your organs to see if anything is abnormal.

Vulvar biopsy

Your healthcare provider may take a sample of your vulvar tissue. This is called a biopsy. The biopsy can be done in your healthcare provider's office. Your care team will send the tissue to a lab to be checked for signs of cancer.

Imaging scans

Your healthcare provider may also do other tests, such as imaging scans. They will use the images from these scans to find and diagnose cancer and plan your treatment. If you need to have a scan, your nurse will give you more information.

You may need to get contrast the day of your scan. Contrast is a special dye that helps make the images from your scan clearer. Your doctor or nurse will tell you if you'll get contrast.

Computed tomography (CT)

CT scan uses x-rays to take a fast series of images of the inside of your body. A computer linked to the x-ray machine puts these pictures together to make 3D images. These images show bone, organs, muscles, tumors, and other soft tissue.

Magnetic resonance imaging (MRI)

MRI uses strong magnetic fields to make detailed pictures of the inside of your body. A computer linked to the MRI machine puts these pictures together to make 3D images. These images show bone, organs, muscles, tumors, and other soft tissue.

Positron emission tomography (PET)

A PET scan uses small amounts of radioactive medicine called tracer to make images of the inside of your body. Your healthcare provider will inject (put) a small amount of tracer into one of your veins. The tracer is used by your cells and doesn't stay in your body long. It leaves your body mainly through your urine (pee).

PET-CT

A PET-CT scan combines the images from a PET scan and a CT scan. These scans are done at the same time on the same machine.

Stages of cancer

Stages are a way to describe cancer. Cancer stages are based on where the cancer is, how big it is, and if it has spread. Knowing the stage of cancer will help your healthcare provider make the best treatment plan for you.

Metastatic cancer

Metastatic cancer is when cancer has spread beyond where it started. Cancer can spread:

- Into nearby tissue.
- To your lymphatic system and then to other areas in your body. Your lymphatic system helps your body fight infections. It has tiny, bean-shaped organs called lymph nodes.
- To your blood vessels and then to other areas in your body.

Your healthcare provider will talk with you about the stages of cancer. Read the "Stages of vulvar cancer" section of this resource for more information.

Recurrent cancer

Recurrent cancer is cancer that has come back after it has been treated. Recurrent vulvar cancer can come back in your vulva or in other parts of your body.

Stages of vulvar cancer

Stage I

The cancer is only in your vulva or perineum. It hasn't spread to your lymph nodes or other parts of your body. This stage is divided into stage IA and stage IB.

Stage IA

The cancer is 2 centimeters (about 0.8 inches) or smaller. It hasn't spread more than 1 millimeter deep into your vulvar tissue.

Stage IB

The cancer is more than 2 centimeters, it has spread more than 1 millimeter deep into your vulvar tissue, or both.

Stage II

The cancer has grown into tissues near your vulva and perineum. This includes the lower part of your urethra, vagina, or anus. It hasn't spread to your lymph nodes or other parts of your body. It can be any size.

Stage III

The cancer has spread to lymph nodes near your vulva.

Stage IV

The cancer has spread to other places near your vulva or to distant organs. This stage is divided into stage IVA and stage IVB.

Stage IVA

The cancer has spread to any of the following places near your vulva:

- Your upper urethra.
- Your vaginal mucosa, bladder mucosa, or rectal mucosa.
- Fixed or ulcerated inguinal-femoral (UL-ser-ay-ted IN-gwih-nul FEM- ruhl) lymph nodes in your groin. Fixed means the lymph nodes do not move when you feel them.

Stage IVB

The cancer has spread to distant parts of your body.

How to treat vulvar cancer

Treatment for vulvar cancer depends on:

- The size and location of the cancer.
- If the cancer has spread.
- Your overall health.

Your healthcare provider will talk with you about which treatment is right for you. Your nurse will give you information about the type of treatment you're having.

Surgery

Surgery is the main treatment for vulvar cancer. Your healthcare provider may remove a large amount of tissue if there is cancer in more than one area. They may also need to remove lymph nodes in your groin area if the tumor:

- Is large (more than 2 centimeters).
- Has grown deeply into your vulva.

You may have vulvar reconstruction as part of your surgery. If you do, you will also meet with a plastic surgeon to plan your care.

There are 4 main types of vulvar surgery:

Laser surgery

Laser surgery is the use of a focused beam of light that burns cells off your skin. This is only used to treat precancerous conditions.

Wide local excision

A wide local excision is the removal of the tumor and some nearby tissue. The nearby healthy tissue is removed to make sure all of the cancer is gone.

Vulvectomy

A vulvectomy is the removal of all or part of your vulva.

- **Partial vulvectomy:** Your surgeon will remove the part of your vulva where the cancer is.
- **Simple vulvectomy:** Your surgeon will remove your entire vulva.
- **Radical vulvectomy:** Your surgeon will remove part or all of your vulva and nearby tissue.

Lymph node dissection

A lymph node dissection is the removal of 1 or more lymph nodes.

- **Sentinel node dissection:** Your surgeon will remove only the first nodes that drain the area near the cancer.

- **Complete lymph node dissection:** Your surgeon will remove all of the lymph nodes near your vulva. This can be done on 1 or both sides of your perineum. This surgery increases the risk of lymphedema (swelling) in your leg on the side the nodes were removed.

What to expect after surgery

You will need time to heal and recover after surgery. Recovery time depends on which surgery you had and how much tissue was removed. Some women need longer to heal than others. Ask your healthcare provider what to expect.

The area where you had surgery will be sore for a few weeks after your surgery. You will get pain medicine while you're in the hospital. You will also get a prescription for pain medicine before you go home.

You may also go home with drains in or around your incision. If you do, your nurse will teach you how to care for them before you leave the hospital.

You will see your surgeon 7 to 10 days after your surgery. They will check your surgery site and remove any stitches and drains.

Sitting may be painful for 3 to 4 weeks after your surgery. You will be able to lie down and stand. If you had major surgery or reconstructive surgery, you may not be able to sit for up to 8 weeks.

Radiation therapy

You may have radiation therapy if the cancer has spread to other areas in your body. This includes your lymph nodes or other organs. Radiation therapy can also be used before surgery to shrink the tumor.

There are 2 main types of radiation therapy:

- **External beam radiation therapy**: This is the most common type of radiation therapy. It is done using a machine outside of your body.
- **Brachytherapy**: This is done internally using radioactive implants. Internally means it is done from inside your body.

Chemotherapy

If you're having chemotherapy (chemo), your nurse will give you information about the chemo medicines you will get.

Biologic therapy

Biologic therapy uses your immune system to boost, direct, or restore your body's natural defenses to fight against cancer. This treatment uses substances made by your body or in a laboratory. Biologic therapy is also called biotherapy or immunotherapy.

Your healthcare provider may test your blood and tumors for certain genes that could make you eligible for immunotherapy.

Clinical trials

Clinical trials are a type of research study. They can help us find the best treatments for cancer. Clinical trials can also help find ways to manage cancer symptoms and side effects of treatment.

Ask your healthcare provider about clinical trials for vulvar cancer. Read *What Is a Clinical Trial?* (www.mskcc.org/cancer-care/clinical-trials/what-clinical-trial) or visit www.cancer.gov/clinicaltrials/education/what-is-a-clinical-trial for more information.

What to do after treatment for vulvar cancer

After you finish your treatment, your healthcare provider will give you a follow-up care plan. The plan explains what exams and tests you should have in the future and how often you should have them. Following the plan can help your healthcare provider notice recurrent vulvar cancer or new cancer.

After your treatment, use a mirror to look at the area around your vulva every month. Ask your nurse to show you how to use a mirror to do this. If you notice any changes or symptoms, call your healthcare provider. Don't wait until your next follow-up appointment.

After you finish your treatment, try to:

- Maintain a healthy weight.

Eat a balanced diet. Read *Eat Your Way to Better Health* (www.mskcc.org/pe/eat-better-health) for more information about healthy eating after cancer treatment.

- Exercise. This will help you build strength and energy. Talk with your healthcare provider about which exercises are safe for you.
- Stop smoking, if you smoke. MSK has specialists who can help you quit smoking. Call 212-610-0507 or ask your nurse about for more information about our Tobacco Treatment Program.

MSK resources

Emotional support

Having cancer can cause many emotions. Recovering from cancer treatments can take time. Please take advantage of our staff's experience. They can help you at every step and can refer you to other professionals if needed. Let us know how you're feeling and what we can do to help.

Counseling center

Coping with vulvar cancer can be difficult. You may want help dealing with its emotional impact on you and your family and friends. If you have questions or worries, or if you feel anxious or depressed, talk with the members of your healthcare team. They can also refer you to a counselor who can help you express, understand, and cope with your feelings.

Support groups

MSK offers support groups for people with cancer. Groups are a way for people with cancer to support each other. They can help you understand your feelings and experiences. Talk to your healthcare provider about support groups that are available to you.

Sexual health

You may have questions about sex. You can discuss them with your healthcare provider, nurse or social worker. You can also speak with someone from MSK's Female Sexual Medicine Women's Health Program. For more information or to make an appointment, call 646-888-5076.

Social work

A social worker can provide emotional support and suggest resources for financial aid, transportation, and home care.

Integrative Medicine and Wellness Service

MSK's Integrative Medicine and Wellness Service offers many therapies to complement (go along with) traditional medical care. They offer:

- Massage
- Acupuncture
- Hypnotherapy
- Meditation
- Visualization and other mind-body therapies
- Music therapy
- Nutritional counseling
- Classes in yoga, t'ai chi, and aerobics

To make an appointment for Integrative Medicine and Wellness Service's therapies, classes, and workshops, call 646-449-1010. To schedule a consultation with a doctor in the Integrative Medicine and Wellness Service, call 646-608-8550.

When to call your healthcare provider

Call your healthcare provider if you have:

- A fever of 100.5F (38C) or higher
- Chills
- Bad smelling discharge from your surgical area
- Pain that's getting worse
- Swelling in your groin or thighs that's getting worse
- Trouble breathing
- Pain or redness in your calves
- Shortness of breath or pain when you breathe

Resources

American Cancer Society (ACS)

www.cancer.org
800-227-2345
Offers a variety of information and services, including Hope Lodge, a free place for patients and caregivers to stay during cancer treatment.

Cancer*Care*

www.cancercare.org
800-813-4673
275 7th Ave. (between 25thand 26th streets)
New York, NY 10001
Provides counseling, support groups, educational workshops, publications, and financial assistance.

National Cancer Institute
www.cancer.gov
800-4-CANCER (800-422-6237)

OncoLink
www.oncolink.upenn.edu
Provides information about specific types of cancer, updates on cancer treatments, and news about research advances.

The Wellness Community
www.wellness-community.org
Provides professionally led support groups nationwide and education, stress management, and social networking in a home-like community setting with a focus on enhancing health and well-being.

Society of Gynecologic Oncology
www.sgo.org/patients-caregivers-survivors
The SGO's mission is to support research, education and public awareness of gynecologic cancer prevention, early diagnosis, and optimal treatment. This page offers information for people affected by gynecologic cancers and their caregivers.

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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