

# Vulvar Cancer: Know What to Expect

## For people with vulvar cancer

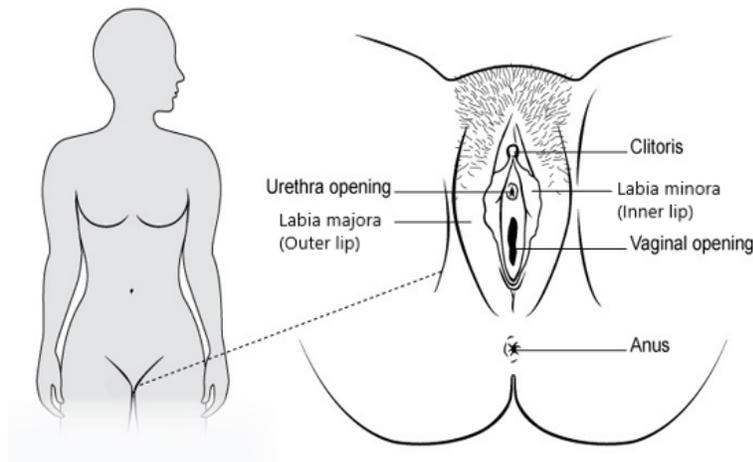
Read this pamphlet to learn about:

- What is vulvar cancer
- How vulvar cancer is treated
- Ways to cope
- Questions to ask your doctor



## What is the vulva?

The vulva is the external (outside) part of the female genitals. The vulva includes the outer and inner lips (both the labia majora and minora), the clitoris, and the openings to the urethra and the vagina.



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## What is vulvar cancer?

Vulvar cancer is a disease in which normal cells of the vulva begin to change, grow out of control, and form a mass of cells called a tumour. Vulvar cancer usually affects the outer lip, but may also affect the inner lip or the clitoris.

The 3 main types of vulvar cancer are:

- **squamous cell carcinoma** – Starts in the thin, flat skin cells. This type is usually found on the vulva, the outer and inner lips.
- **melanoma** – Starts in the pigmented skin cells and can be found on the vulva or in the vagina.
- **adenocarcinoma** – Starts in the cells that make mucus and other fluids. This type is usually found on the sides of the vaginal opening.

## What does stage mean?

The stage is a way of describing the extent of spread of a cancer.

Stage can describe:

- where the cancer is located
- if or where it has spread
- if it is affecting other organs in the body

There are 4 stages of vulvar cancer (Stage 1 to Stage 4). Your doctor will use the stage of your cancer to decide which treatment is best for you.

**Stage 1:** Tumour is found only in the vulva or perineum (area between the anus and the vagina).

**Stage 2:** Tumour is any size and has spread into the lower part of the urethra, the lower part of the vagina, or the anus. Cancer has not spread to the lymph nodes.

**Stage 3:** Tumour is any size and has spread into the upper part of the urethra, the upper part of the vagina, bladder or the anus. Cancer has spread to one or more nearby lymph nodes.

**Stage 4:** Tumour is any size and has spread into the pelvic bone, lymph nodes or to others parts of the body.

## **Has your cancer spread?**

The process used to find out if cancer has spread within the vulva or to other parts of the body is called staging.

The information gathered determines the stage of the disease. It is important to know the stage in order to plan treatment.

The following tests and procedures may be used in the staging process:

### **Pelvic exam**

- An exam of the vulva, vagina, cervix, uterus, fallopian tubes, ovaries, and rectum. A speculum is inserted into the vagina and the doctor looks at the vagina and cervix for signs of disease.
- A Pap test of the cervix is usually done. The doctor also inserts one or two lubricated, gloved fingers of one hand into the vagina and places the other hand over the lower abdomen to feel the size, shape, and position of the uterus and ovaries. The doctor also inserts a lubricated, gloved finger into the rectum to feel for lumps or abnormal areas.

### **Colposcopy**

- A procedure in which a colposcope (a lighted, magnifying instrument) is used to check the vagina, cervix, vulva, perineum and perianal areas for any abnormalities. Tissue samples may be taken and checked under a microscope for diagnosis.

### **CT scan (CAT scan)**

- A procedure that provides detailed pictures of areas inside the body, taken from different angles. The pictures are made by a computer linked to an x-ray machine. You may need to either swallow a liquid or have a dye injected into a vein to help the organs or tissues show up more clearly. This test is also called computed tomography, computerized tomography, or computerized axial tomography.

## **MRI (magnetic resonance imaging)**

- A procedure that uses a magnet, radio waves, and a computer to make a series of detailed pictures of areas inside the body. A dye may be injected into a vein to help the organs or tissues show up more clearly. This test is also called nuclear magnetic resonance imaging (NMRI).

## **PET scan (positron emission tomography scan)**

- A test to find malignant tumour cells in the body. A small amount of radioactive glucose (sugar) is injected into a vein. The PET scanner rotates around the body and makes a picture of where glucose is being used in the body. Malignant tumour cells show up brighter in the picture because they are more active and take up more glucose than normal cells do.

## **How does cancer spread in the body?**

Cancer can spread locally through tissue, the lymph system, and the blood:

- **Locally:** The cancer spreads from where it began by growing into nearby tissues.
- **Lymphatic system:** The cancer spreads from where it began by getting into the lymphatic system. The cancer travels through the lymphatic vessels to other parts of the body.
- **Blood:** The cancer spreads from where it began by getting into the blood. The cancer travels through the blood vessels to other parts of the body.

## **How is vulvar cancer treated?**

The treatment of vulvar cancer depends on:

- the size and stage of the tumour
- the type of vulvar cancer
- whether the cancer has spread
- your overall health

The goal of surgery is to remove all the cancer while minimizing the physical changes that may affect bladder and bowel functions, as well as, sexual function and wellbeing. One of the following types of vulva surgery may be done.

**Vulvectomy:** a surgery to remove part or all of the vulva.

- **Wide local excision of vulva:** This involves removing the lesion on the vulva with some normal skin and tissue around the lesion. Another name for this procedure is simple vulvectomy.
- **Radical vulvectomy:** This involves removing the lesion on the vulva with a larger area of skin (1 to 2 centimeters) and deeper tissue.

If you are diagnosed with vulvar cancer, some of the lymph nodes in the groin may be removed. This will have been discussed with your doctor..

There are different types of surgery to remove lymph nodes from the groin:

- **Inguinofemoral lymphadenectomy:** Through a small incision (cut) in the groin, lymph nodes that are close to the skin's surface and possibly deeper lymph nodes of the groin are removed.
- **Sentinel lymph node biopsy of the inguinal nodes:** Involves removing the first lymph node in the groin that drains the vulva. This lymph node is found by using different tests, including the injection of blue dye, ICG or radioactive material into the cancer on the vulva. The first lymph node to receive the substance or dye is removed and analyzed by the pathologist (specialist who examines tissues).

Radiation and chemotherapy can be used as the main treatment for vulvar cancer when:

- the tumour is too large to remove,
- the tumour is very close to the urethra or anus, and
- removing the tumour could cause serious side effects

Radiation therapy and chemotherapy may also be used after surgery as an additional treatment to kill any cancer that may contain microscopic cancer cells. Treatment given after surgery lowers the risk of the cancer coming back.

Most side effects of vulvar cancer treatment can often be prevented or managed with help from your health care team. Talk with your doctor about all treatment options.

## Coping with vulvar cancer

Dealing with the news of a cancer diagnosis can be very difficult. You are not alone. Your health care team is here for you so feel comfortable speaking with them about your concerns and needs. As a patient in the Princess Margaret Cancer Program, you have access to many resources to help you cope. These include:

- **social workers** who can help you better cope with your illness
- **clinical dietitians** that specialize in cancer and can help you with your nutrition and diet concerns
- **Cancer Rehab and Survivorship Program** which has programs and services to help you cope with cancer and its treatment.
- **Patient & Family Library** where you can ask a Librarian to search for specific health information and borrow books, videos, audiobooks and DVDs

For more information about the services available to you or to contact a social worker or dietitian, speak to a member of your health care team.

To contact the Cancer Rehabilitation and Survivorship program visit:

Cancer Survivorship Centre located on the 2nd floor of Princess Margaret Cancer Centre

- Website: [https://www.uhn.ca/PrincessMargaret/Clinics/Cancer\\_Rehab\\_Survivorship](https://www.uhn.ca/PrincessMargaret/Clinics/Cancer_Rehab_Survivorship)

Princess Margaret Patient & Family Library located in the atrium on the main floor of Princess Margaret Cancer Centre

- Website: [https://www.uhn.ca/PrincessMargaret/PatientsFamilies/Specialized\\_Program\\_Services/Pages/princess\\_margaret\\_patient\\_family\\_library.aspx](https://www.uhn.ca/PrincessMargaret/PatientsFamilies/Specialized_Program_Services/Pages/princess_margaret_patient_family_library.aspx)

ELLICSR: Health, Wellness & Cancer Survivorship Centre located in the basement of the Clinical Services Building in the Toronto General Hospital

- Website: [https://www.uhn.ca/PrincessMargaret/PatientsFamilies/Specialized\\_Program\\_Services/Pages/ellicsr\\_health\\_wellness\\_cancer\\_survivorship.aspx](https://www.uhn.ca/PrincessMargaret/PatientsFamilies/Specialized_Program_Services/Pages/ellicsr_health_wellness_cancer_survivorship.aspx)

## Questions to ask your doctor

Speaking to your health care team is important in helping you make decisions about your health care. Sometimes preparing a list of questions you want to ask can be helpful.

### Here is a list of common questions you may want to ask your doctor:

1. What type of vulvar cancer do I have?
2. Can you explain my pathology report (test results) to me?
3. What stage is the vulvar cancer?
4. Has cancer spread to my lymph nodes or anywhere else?
5. Would you explain my treatment options? What clinical trials are open to me?
6. How will this treatment benefit me?
7. How will this treatment affect my daily life? Will I be able to work, exercise, and do my usual activities?
8. Will this treatment affect my ability to become pregnant or have children?
9. How will my cancer affect my sex life?
10. What is the expected timeline for my treatment plan?
11. What are the possible long-term side effects of my cancer treatment?
12. How serious is my cancer?
13. What are my chances of survival?
14. Where can I find emotional support for me and my family?
15. Whom do I call for questions or problems?
16. Is there anything else I should be asking?



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