Vulvar Cancer: Know What to Expect

For women with vulvar cancer

What is the vulva?
The vulva is the external (outside) part of the female genitals. The vulva includes the outer and inner lip, the clitoris, and the openings to the urethra and the vagina.

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 2 main types of vulvar cancer are:

- **squamous cell carcinoma** – Starts in the thin, flat skin cells. This type is usually found on the vaginal lips.
- **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 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 rectum 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 may have spread into the lower part of the urethra, the lower part of the vagina, or the anus. Cancer has spread to one or more nearby lymph nodes.

**Stage 4:** Tumour has spread into the upper part of the urethra, the upper part of the vagina, 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 from the staging process 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 vagina, cervix, uterus, fallopian tubes, ovaries, and rectum. A speculum is inserted into the vagina and the doctor or nurse looks at the vagina and cervix for signs of disease. A Pap test of the cervix is usually done. The doctor or nurse 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 or nurse 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 and cervix for abnormal areas. Tissue samples may be taken using a curette (spoon-shaped instrument) or a brush and checked under a microscope for signs of disease.

CT scan (CAT scan)

• A procedure that makes a series of detailed pictures of areas inside the body, taken from different angles. The pictures are made by a computer linked to an x-ray machine. A dye may be injected into a vein or swallowed to help the organs or tissues show up more clearly. This procedure 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. This procedure is also called nuclear magnetic resonance imaging (NMRI).

PET scan (positron emission tomography scan)

• A procedure to find malignant tumor 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 tumor 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 through tissue, the lymph system, and the blood:

• **Tissue.** The cancer spreads from where it began by growing into nearby areas.

• **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 without any loss of the woman's sexual function. One of the following types may be done.

There are different types of surgery for the vulva:

**Wide local excision of vulva:**
- This involves removing the lesion on the vulva with some normal skin and tissue around the lesion. Other names for this procedure are partial simple vulvectomy.

**Radical wide local excision of vulva:**
- This involves removing the lesion on the vulva with a larger area of skin (1 to 2 cm) and deeper tissue. Other names for this procedure include modified radical vulvectomy.

If you have a diagnosis of 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 for removal of lymph nodes from the groin:

**Inguinofemoral lymphadenectomy:**
- Through small cuts at the groin, lymph nodes that lie close to skin surface and possibly the deep 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 injecting either blue dye or radioactive material into the cancer on the vulva the morning of your surgery. The first lymph node to receive the substance or dye is removed.
Vulvectomy: a surgical procedure to remove part of all of the vulva:

- Skinning vulvectomy: the top layer of vulvar skin where the cancer is found is removed. Skin grafts from other parts of the body may be needed to cover the area where the skin was removed.
- Modified radical vulvectomy: surgery to remove part of the vulva, nearby lymph nodes may also be removed.
- Radical vulvectomy: surgery to remove the entire vulva. Nearby lymph nodes are also removed.

Radiation and chemotherapy can be used as primary treatment for vulvar cancer when the tumour is too large to remove without damaging local structures like the vagina or anus.

Radiation therapy and chemotherapy may also be used after surgery to kill any cancer cells that are left. Treatment given after surgery will lower 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
• the Cancer Rehab and Survivorship Program which has programs and services to help you cope with cancer and its treatment, including:
  • a 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
• Princess Margaret Patient & Family Library located in the atrium on the main floor of Princess Margaret Cancer Centre
• ELLICSR: Health, Wellness & Cancer Survivorship Centre located in the basement of the Clinical Services Building in the Toronto General Hospital
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?

Visit www.uhnpatienteducation.ca for more health information. The development of patient education resources is supported by the Princess Margaret Cancer Foundation.

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