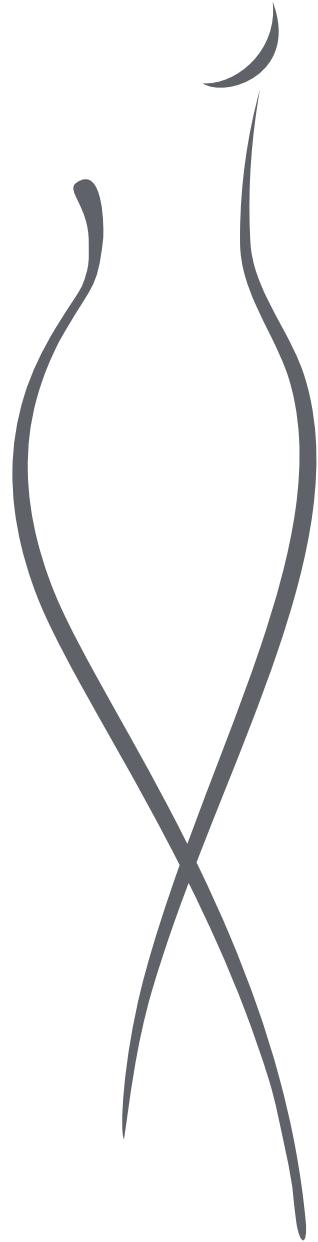


Understanding Vulvar Cancer

This booklet covers what you need to know about vulvar cancer, key treatments, tips to prepare for the changes ahead, as well as where you can find more information and support.

We know this is a very difficult time for patients and their families. There is much you can do to play an active part in your care. Knowing more about vulvar cancer will help you make informed decisions. To learn more, review this booklet closely and speak to your treatment team.



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Dedication

Margaret Keough

The idea for this patient booklet was inspired by Margaret Keough, it was her hope to raise awareness and support of vulvar cancer.



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We would like to thank the MUHC Patient Education Office for their support throughout the development of this material, including the writing, the design, layout, as well as for the creation of all the images.

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IMPORTANT: PLEASE READ

Information provided by this booklet is for educational purposes. It is not intended to replace the advice or instruction of a professional healthcare practitioner, or to substitute medical care. Contact a qualified healthcare practitioner if you have any questions concerning your care.

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Health Centre

**Office d'éducation des patients
Patient Education Office**



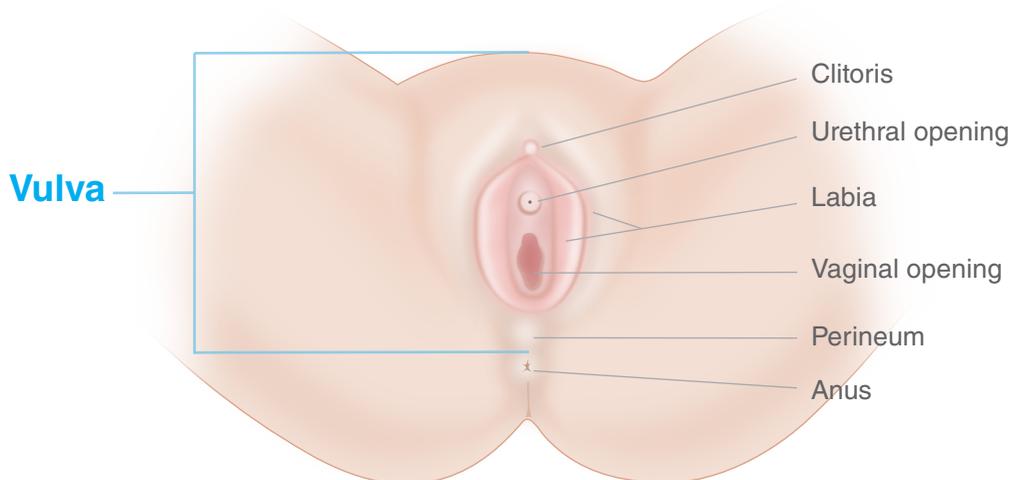
This material is also available through the MUHC Patient Education Office website www.muhcpatienteducation.ca

What is vulvar cancer?

What is a vulva?

The **vulva** refers to all of the outside parts of a woman's genitals. It is made up of the:

- **Clitoris**
The clitoris is found at the front or top of the vulva and helps with sexual pleasure.
- **Urethral opening**
The urethra is a tube that carries urine from the bladder to the outside of the body
- **Labia**
These inner and outer layers protect the vagina and urethra.
- **Vaginal opening**
This is the canal that connects the womb (or uterus) to the outside world. During labor, a baby passes through this canal to be born.
- **Perineum**
The skin found between the vaginal opening and the anus.

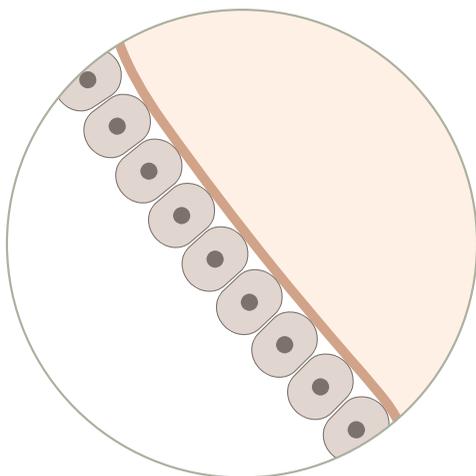


What is vulvar cancer?

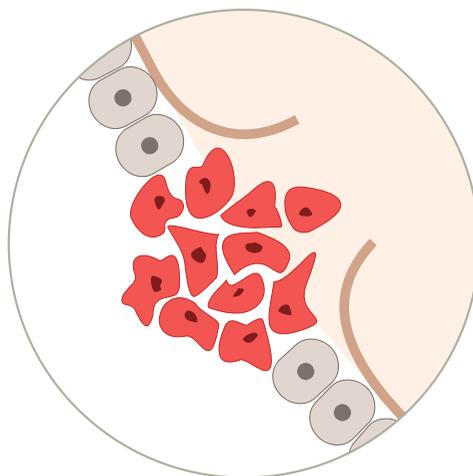
Cancer is a disease that starts in your cells. To better understand **vulvar cancer**, we first need to understand cancer and how **cells** grow in your body. Your cells are the building blocks that make up all the tissues and organs of your body. There are billions of cells in your body (e.g. heart cells, brain cells, stomach cells, bone cells).

When a cell gets old and is damaged, your body repairs it and clears it away. A brand new cell then grows and takes its place. In this way, your cells are constantly being replaced by new cells in a controlled and orderly way.

When cells change and grow out-of-control, we call this **cancer**.



Healthy cells



Cancer

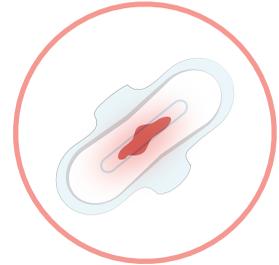
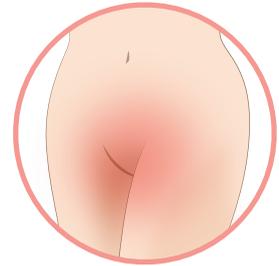
Vulvar cancer is a type of cancer that begins in the vulva. With cancer, your body is making more cells than your body needs. Over time, these extra cells in your vulva will form a lump, or sore. This is also called a **malignant mass**, or **cancer tumour**.

What changes you might notice

People often notice changes when they get sick. These may be changes in the body that anyone can see (e.g. redness on your skin). We call these **signs**. These could also be changes that you can feel, but cannot see (e.g. pain). We call these **symptoms**.

Vulvar cancer often appears as a lump or sore on the vulva. You might also notice these signs and symptoms:

- Itchiness on your vulva (which does not go away)
- Change in the color of the vulva – parts of the vulva may start to appear white, grey, pink, reddish, or dark brown
- Scaly, hard, or wart-like patches
- Thickened skin
- Vaginal bleeding that isn't from a period (**menstruation**)
- Pain, tenderness or discomfort in your vulva



DID YOU KNOW?

Many of these changes may not be caused by cancer. They could be due to another health problem. The best way to know the cause is by talking to your doctor and having a check-up.

What are the risk factors?

A risk factor is anything that increases the chances of developing a disease. This could be:

- An **action** (e.g. smoking)
- A **trait** or **feature** (e.g. your age)
- A **health problem** (e.g. an illness you might have had)

Knowing the risks factors and having healthy living habits (such as not smoking and keeping a healthy body weight) may lower the chances of a person getting cancer. That said, having one or a few risk factors does not mean that you will get cancer. A person can also develop cancer without having any risk factors.

You are more likely to have vulvar cancer, if you have had:

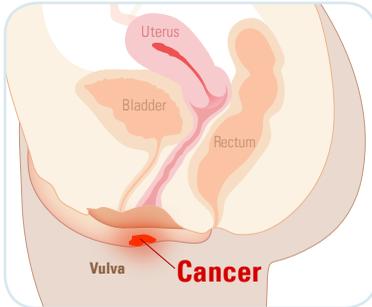
- **Human papilloma virus (HPV) infection:** This is a **sexually transmitted infection**. It is passed on from one person to another through sexual contact.
- **Vulvar skin problems** (e.g. Lichen's sclerosus or Lichen's planus) or skin conditions that caused color changes, itchiness or pain around your genitals.
- **Vulvar intraepithelial neoplasia (VIN):** a **pre-cancer condition** where vulvar cells have begun to change. If left untreated, VIN may lead to cancer.
- **Weak immune system:** Your immune system keeps your body healthy and well-balanced by defending your body from tiny, invisible germs, such as bacteria and viruses.
- **Cervical, vaginal or anal cancer.**
- **Smoking** also increases your chances for vulvar cancer.



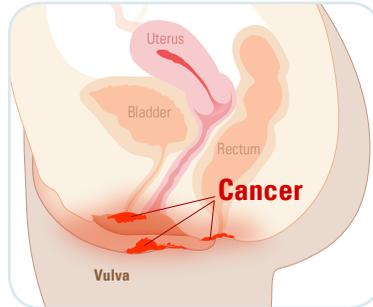
What is vulvar cancer staging?

Your doctor will want to know the stage of your vulvar cancer. **Staging** describes how far along the cancer cells have grown and if they have spread to other parts of the body. In other words:

Staging tells us how advanced the cancer is. Knowing the stage of cancer helps plan your care.



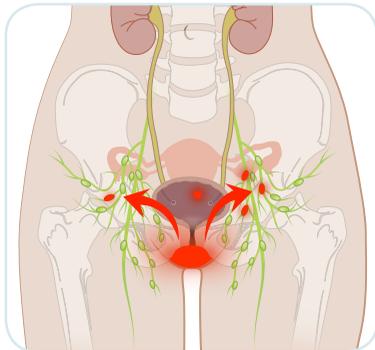
Stage 1: Cancer found in the vulva or perineum. It has not spread to other parts of your body.



Stage 2: Cancer has spread to the lower parts of the urethra, vagina, or the anus.

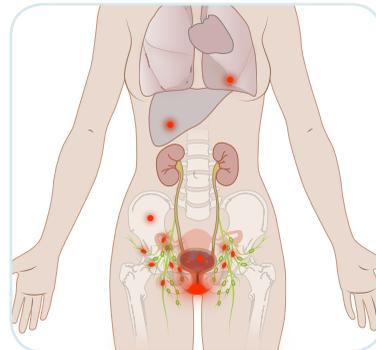


Stage 3: Cancer has spread to nearby **lymph nodes**. Lymph nodes protect you from infection and are located throughout your body. *(See page 8 to learn more)*



Stage 4A: Cancer has spread to:

- the upper parts of the urethra or vagina, or to nearby tissues such as the bladder or rectum.

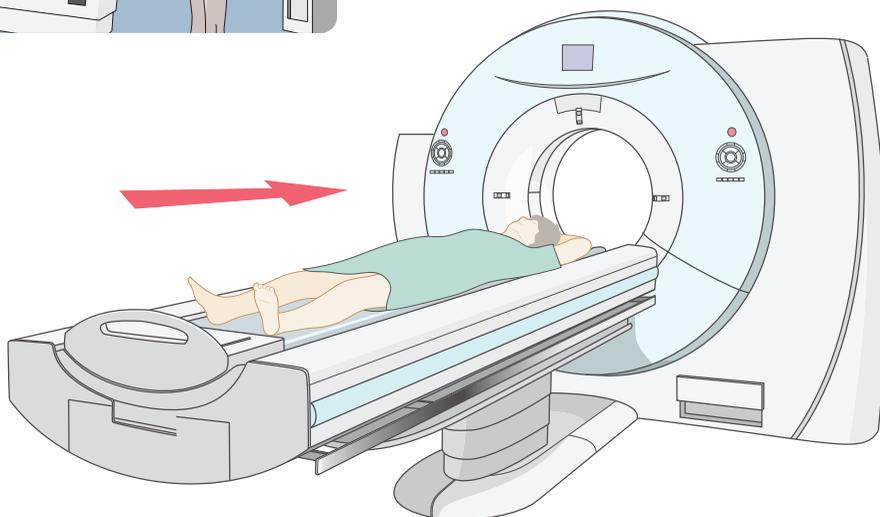
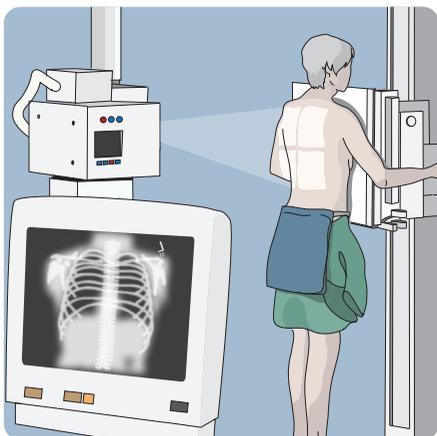


Stage 4B: Cancer has spread to the lymph nodes of the pelvis or to distant parts of your body such as your lungs, liver, or bones.

What is vulvar cancer staging?

Staging tests your doctor may suggest

Taking pictures of your bones, chest or abdomen can help us see if the cancer has spread to these areas. There are many different types of tests (e.g. x-ray, computed tomography (CT) scan, magnetic resonance imaging (MRI) or positron emission tomography (PET).) While each test is a little different, in the end, the information gathered from the pictures helps your team better understand what is happening in your body.



What are the treatments?

The 3 main treatments for vulvar cancer are:

1. Surgery
2. Radiation therapy, and in some cases
3. Chemotherapy

You may have just one or a combination of any of these treatments. Your unique treatment plan will depend on:

- The stage of the cancer
- Where the cancer is found on your vulva,
- Your overall general health

You and your team will decide together on the best treatment for you.



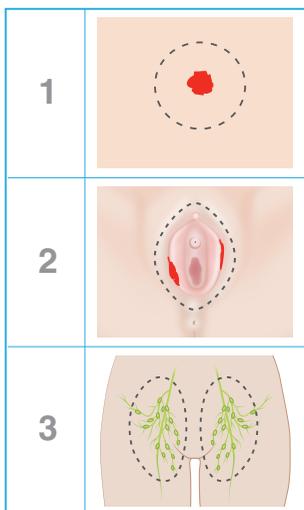
Surgery

For some people, surgery is the best way of treating vulvar cancer. For this reason, it is very likely part of your treatment plan.

During surgery, your doctor will take out the tumour mass. Some of the tissue around the cancer in the vulva will also be removed. How much is removed during the surgery will depend on:

- The type of cancer cells
- The size of the cancer
- Where the cancer is found
- Whether the cancer has spread

The main types of surgeries are:



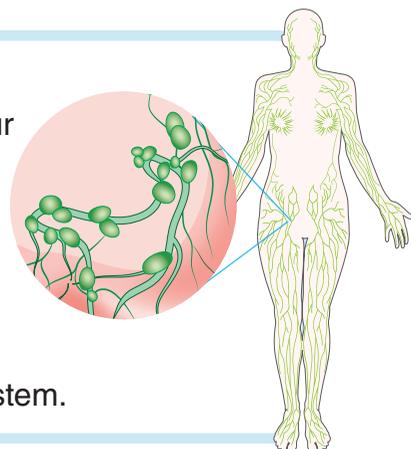
1. Wide local excision : Your surgeon will remove the cancer and some healthy tissue around the cancer.

2. Hemi or total vulvectomy : This surgery is done when the cancer has spread deep under the skin. Your surgeon will remove the cancer and some healthy tissue around the cancer. Either one or both sides of the vulva are also removed, depending on where the cancer is located.

3. Inguinal lymph node dissection : Your surgeon will remove the **lymph nodes** from one or both sides of the groin.

What are lymph nodes?

Lymph nodes are small bean-shaped filters in your body that remove anything that does not belong (e.g. bacteria, viruses, dead cells, debris and cancer cells). They are part of the **lymphatic system**, which (very much like your blood vessels) is spread throughout your body. This system works to manage fluids in your body, and plays an important role in your body's immune system.



Surgery

Depending on your unique situation, you may have just one or a combination of the surgeries described above. Some patients may also need other types of surgeries. Your surgeon will explain what surgery plan is best for you.

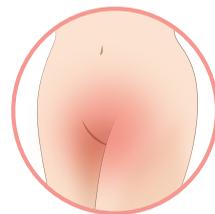
Changes you may notice after surgery

After your vulvar surgery, you may have some unwanted reactions. We call these **side effects**.

Side effects are different for everyone, and will depend on what surgery you have. Some people have few side effects. For others, the side effects may be more troublesome. The good news is that most side effects are usually temporary and can be managed.

After vulvar surgery, you may notice:

- Numbness, tingling, feeling hot or cold in the vulva area
- Pain or discomfort in the vulva area
- Pain, redness, and swelling of the wound
- Changes to the way the vulva looks
- Swelling, redness, or tenderness in the calf of your leg
- Swelling in your legs. (When lymph nodes are removed or damaged, this can cause blocks in your lymphatic system. We call this **lymphedema**. See *page 16 to learn more*.)
- Changes in sexual function such as pain and numbness in the vulva area



Speak to your treatment team if you notice any of these changes. Remember, side effects can usually be controlled or reduced. There are many medications and strategies that can help.

Radiotherapy

Depending on the stage of your vulvar cancer, you may need to have **radiotherapy**. This is the use of special x-rays to treat cancer.

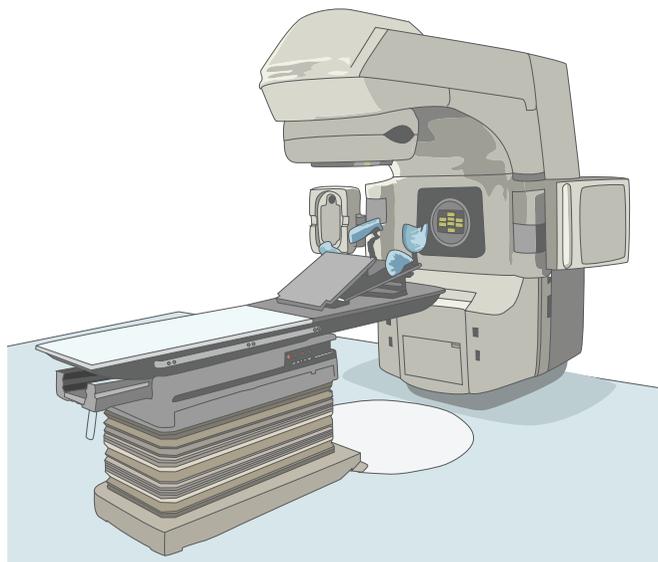
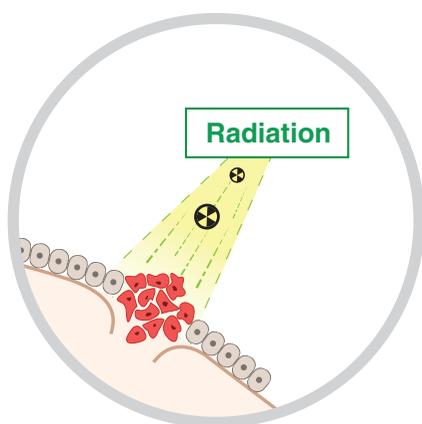
Radiotherapy works by acting on your cells. When radiation enters your body, cancer cells are damaged and lose their ability to make more cancer cells. The goal of radiotherapy is to get enough radiation into the right spot of the body to reach the cancer cells but damage as few healthy cells as possible.

Before starting this treatment, your doctor will organize some tests (e.g. a CT scan, MRI). These tests will help your radiation therapy team plan your treatment.

If radiation therapy is part of your treatment plan, you may receive this every day for several weeks.

There are many different types of radiation therapy. Vulvar cancer is usually treated with **external beam radiation therapy**.

This type of radiation therapy is given from outside of your body. A machine is used to direct radiation x-rays through your skin to the cancer and the area close to the cancer, where there may be nearby cancer cells.



Radiotherapy

Changes you may notice after radiotherapy

After radiation therapy, you may have some unwanted reactions. We call these **side effects**. The side effects you may have will depend on the type of radiation used, the amount of radiation you will have in total, and your overall health.

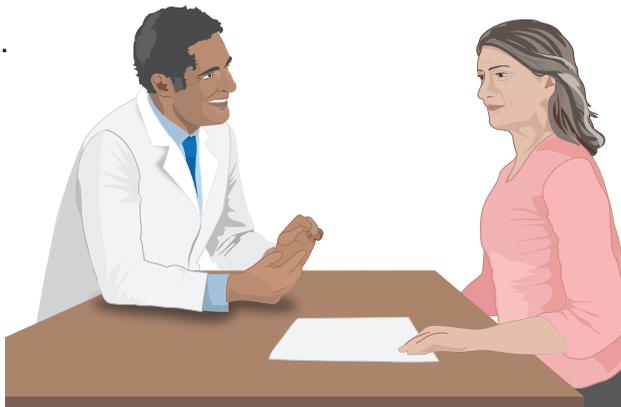
Side effects are different for everyone, and will depend on what treatment you have. Some people have few side effects. For others, the side effects may be more troublesome. The good news is that most side effects are usually temporary and can be managed.

The most common side effects are:

- Moist, red, itchy, painful skin
- Feeling tired (fatigue)
- Diarrhea
- Pain while you urinate or the need to urinate often
- Pain, redness, and swelling of the wound
- Swelling in your legs. (When lymph nodes are removed or damaged, this can cause blocks in your lymphatic system. We call this **lymphedema**. See *page 16 to learn more*.)
- Loss of pubic hair

Side effects are different for everyone. Speak to your treatment team if you notice any of these changes.

Remember, side effects can usually be controlled or reduced. There are many medications and strategies that can help.



Chemotherapy

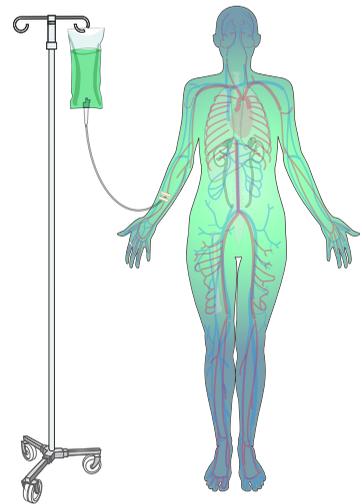
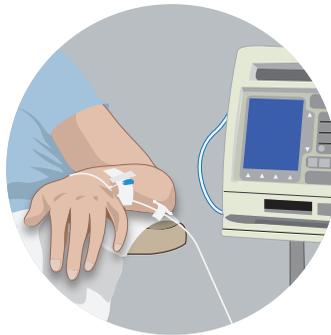
Chemotherapy is the use of powerful medications to kill cancer cells. If your doctor suggests that you have chemotherapy, you may have this treatment on its own or in combination with radiation therapy. Your chemotherapy plan will depend on the type of cancer you have, how advanced it is, your age and your health.

For this reason, chemotherapy is different for everyone. Some people may receive one medication. Other people may need more than one.

Talk with your treatment team if you have questions or concerns. Together, you will discuss what plan might be best for you.

Chemotherapy medications come in different forms (e.g. pills, liquid). The chemotherapy medications used to treat vulvar cancer are in liquid form and usually given through your vein.

We call this **intravenous** or **IV medication**.



Changes you may notice after chemotherapy

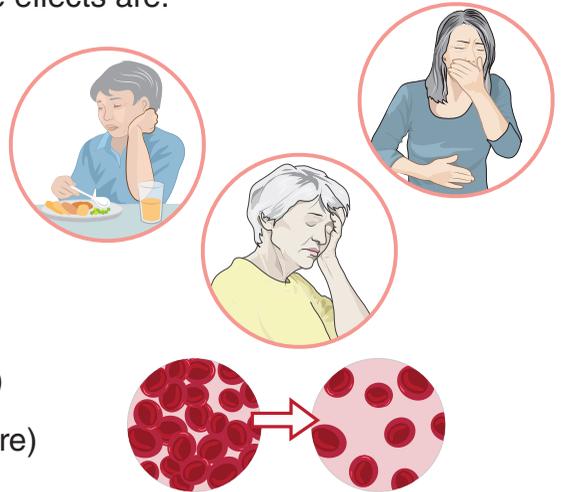
Chemotherapy goes almost everywhere in your body using your **blood vessels** (the system of tubes in your body which carry your blood). It works by destroying fast-growing cells (such as cancer cells). In the same way, chemotherapy can also damage normal, healthy cells that grow quickly (e.g cells that make up your hair, the lining in your mouth, your stomach, and intestine). For this reason, you may have some unwanted reactions, or **side effects**.

Chemotherapy

Side effects are different for everyone, and will depend on what type of chemotherapy you have. Some people have few side effects. For others, the side effects may be more troublesome. The good news is that most side effects are usually temporary and can be managed.

Side effects can happen any time during chemotherapy, immediately after, or a few days or weeks later. Common side effects are:

- Feeling tired (fatigue)
- Loss of appetite
- Nausea and vomiting
- Numb or tingling in the toes or fingers (**neuropathy**)
- Lower blood cell counts (This may increase your chance for an infection.)
- Hearing loss (although, this is quite rare)



Speak to your treatment team if you notice any of these changes. The good news is that these side effects usually get better once your chemotherapy is done. However, until this time, we can control or reduce them. Remember, there are many medications and strategies that can help.

Clinical trials

A clinical trial is a type of research study. They explore new ways to prevent, find and treat cancer. A clinical trial may test a new medication or treatment. Ask your doctor if there are any clinical trials that are right for you.



Living with vulvar cancer

Working through your feelings

Every person's cancer experience is different. For some people, cancer and its treatment have very little or no impact on their life. For others, it seems like it changes everything. Whichever is the case for you, it is normal that you might experience a range of feelings.

Your feelings can change from one day to another, or even within the same day. Talk to the people you trust about your feelings. Speak to your treatment team about your concerns and how you feel. Tell us if you have been feeling sad, anxious or hopeless for a long time.

You are not alone. We are here to help. Please see the section on **“Where to find more information”** to learn more about resources that are available to you.



Coping with long-term side effects

Some changes for women with vulvar cancer may be more long-lasting. These may include:

- Changes in sexual desire or pleasure
- Lymphedema

This section covers what you need to know about these two common long-term side effects. It also reviews tips on what you can do, if you have these side effects.

Changes in sexual desire or pleasure

Vulvar cancer treatment may change the way you experience sexual pleasure. This is due to a number of reasons:

- Surgery and radiotherapy may cause physical changes to your vulva. This may change how you feel about sexual contact.
- Having cancer may affect how you feel about yourself, your relationships, and your comfort with sexual intimacy.
- Your concerns and worries can also greatly influence how you feel and respond sexually.

Remember, this is normal. Reflect on how you are feeling. Discuss your questions and concerns with your partner, a friend or a counselor.

Speak to your healthcare team if you are having difficulty. You are not alone. We are here to help.



Lymphedema

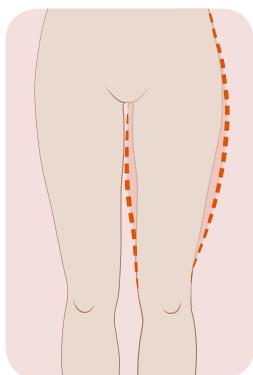
Lymphedema is a swelling that generally appears (for women with vulvar cancer) in one or both of your legs. To understand lymphedema and how to manage it, you need to first understand lymph nodes and how they work in your body.

Lymph nodes are small bean-shaped filters in your body that remove anything that does not belong (e.g. bacteria, viruses, dead cells, debris and cancer cells). They are part of the **lymphatic system**, which (very much like your blood vessels) is spread throughout your body. This system works to manage fluid in your body and plays an important role in your body's immune system.

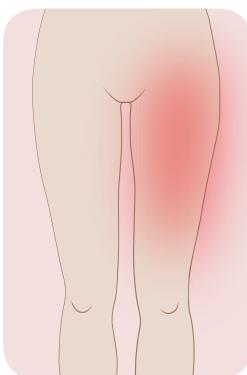
However, when **lymph nodes** are removed or damaged during vulvar surgery and/or radiotherapy, this can cause blocks in your lymphatic system. The extra fluid in your body can no longer drain. It ends up building up in your legs instead.

If you have lymphedema, we will refer you to a specialized team who will teach you about how to manage your lymphedema. Lymphedema is often permanent, but there are ways to help reduce the swelling. You will learn more about this when you meet the lymphedema team.

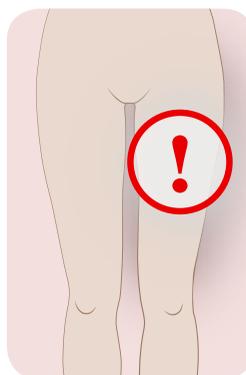
Speak to your healthcare team if you may notice any of the following changes:



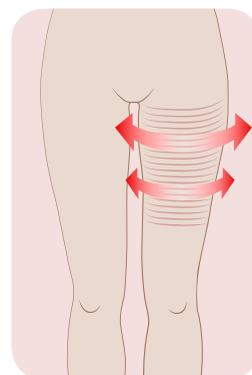
swelling in
your leg



pain in
your leg



difficulty moving
your leg



tightness in
your skin

Your treatment team will confirm whether this is lymphedema. They will also discuss other strategies on how to best manage this with you.

Where to find more information

Many people may try to give you health advice without knowing the details of your cancer and your care. You may also come across information in books or on the internet which is confusing or misleading.



Be careful of the information that comes your way: the internet offers a lot of information. However, some of it is not correct or will not apply to your unique situation.

Write down your questions or bring any information you have to share with your treatment team. We can help you make sense of what you have found as well as learn if and how it may apply to you.

If you are looking for information, contact these groups:

Cedars CanSupport

514-934-1934 ext. 31666
www.cansupport.ca

MUHC Patient Education Office

514-934-1934 ext. 71503
www.muhcpatienteducation.ca

MUHC Psychosocial Oncology Program

514-934-1934 ext 45501
muhc.ca/psychosocial-oncology

Institut National du Cancer (France)

33 (0)1 41 10 50 001
www.e-cancer.fr

Canadian Cancer Society

1-888-939-3333
www.cancer.ca

Ligue Contre le Cancer (France)

0 800 940 939
www.ligue-cancer.net

American Cancer Society

1-800-227-2345
www.cancer.org

Lymphedema Association of Quebec

514-979-2463
www.infolympho.ca

National Cancer Institute

1-800-422-6237
www.cancer.gov

How to reach us

Cedars Cancer Centre

514-934-4400

Cedars CanSupport

514-934-1934 ext 31666

MUHC Psychosocial Oncology Program

514-934-1934 ext 45501



Help Us Help Others

Help support the MUHC Patient Education Office! Donations make a huge difference. They help us create health information materials and programs to deliver the best care for life.

All patient materials are freely available on the internet to MUHC patients, and to patients and families everywhere.

Make a donation through the Cedars Cancer Foundation:

- **In Person /By Mail to:**

Cedars Cancer Foundation - Patient Education Fund

1310 Greene Avenue, Suite 520

Westmount, Qc

H3Z 2B2

514-656-6662

- **Or online:**

www.cedars.ca/cedars/en/donate

Thank you for your support!

