Vulvar Cancer

What is cancer?

The body is made up of trillions of living cells. Normal body cells grow, divide to make new cells, and die in an orderly way. During the early years of a person's life, normal cells divide faster to allow the person to grow. After the person becomes an adult, most cells divide only to replace worn-out or dying cells or to repair injuries.

Cancer begins when cells in a part of the body start to grow out of control. There are many kinds of cancer, but they all start because of out-of-control growth of abnormal cells.

Cancer cell growth is different from normal cell growth. Instead of dying, cancer cells continue to grow and form new, abnormal cells. In most cases the cancer cells form a tumor. Cancer cells can also invade (grow into) other tissues, something that normal cells cannot do. Growing out of control and invading other tissues are what makes a cell a cancer cell.

Cells become cancer cells because of damage to DNA. DNA is in every cell and directs all its actions. In a normal cell, when DNA gets damaged the cell either repairs the damage or the cell dies. In cancer cells, the damaged DNA is not repaired, but the cell doesn’t die like it should. Instead, this cell goes on making new cells that the body does not need. These new cells will all have the same damaged DNA as the first abnormal cell does.

People can inherit damaged DNA, but most often the DNA damage is caused by mistakes that happen while the normal cell is reproducing or by something in our environment. Sometimes the cause of the DNA damage is something obvious, like cigarette smoking. But often no clear cause is found.

Cancer cells often travel to other parts of the body, where they begin to grow and form new tumors that replace normal tissue. This process is called metastasis. It happens when the cancer cells get into the bloodstream or lymph vessels of our body.

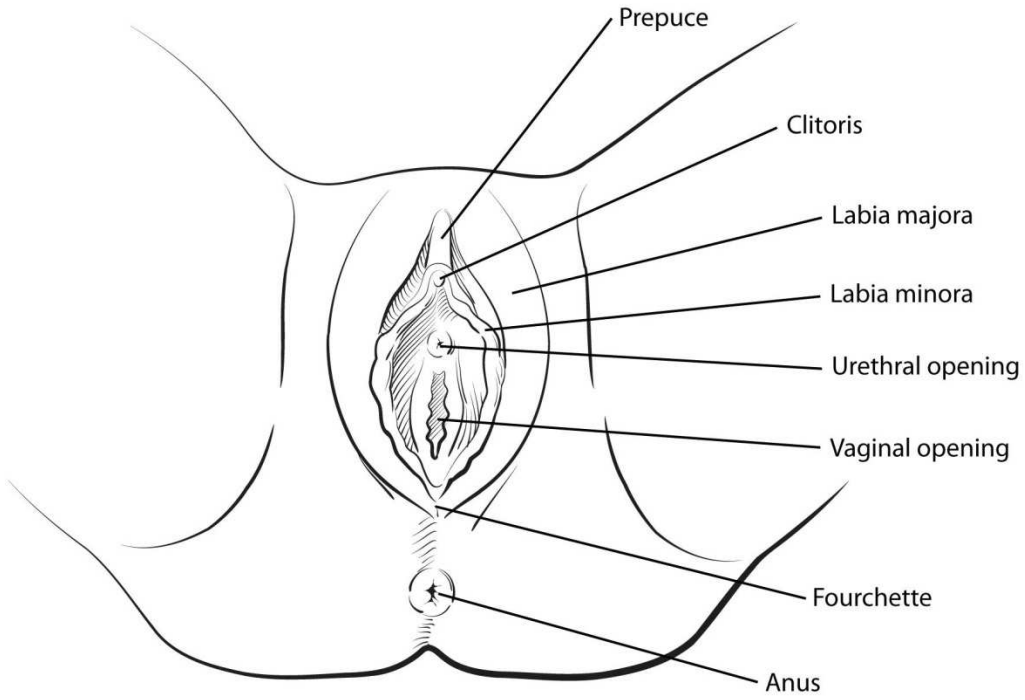
No matter where a cancer may spread, it is always named (and treated) based on for the place where it started. For example, breast cancer that has spread to the liver is still called breast cancer, not liver cancer. Likewise, prostate cancer that has spread to the bone is still prostate cancer, not bone cancer.

Different types of cancer can behave very differently. For example, lung cancer and breast cancer are very different diseases. They grow at different rates and respond to different treatments. That is why people with cancer need treatment that is aimed at their particular kind of cancer.

Not all tumors are cancerous. Tumors that aren't cancer are called benign. Benign tumors can cause problems – they can grow very large and press on healthy organs and tissues. But they can't grow into (invade) other tissues. Because they can't invade, they also can't spread to other parts of the body (metastasize). These tumors are almost never life threatening.

What is vulvar cancer?

The vulva is the outer part of the female genitals. The vulva includes the opening of the vagina (sometimes called the *vestibule*), the labia majora (outer lips), the labia minora (inner lips), and the clitoris.



Around the opening of the vagina, there are 2 sets of skin folds. The inner set, called the *labia minora*, are small and hairless. The outer set, the *labia majora*, are larger, with hair

on the outer surface. The inner and outer labia (Latin for lips) meet, protecting the vaginal opening and, just above it, the opening of the urethra (the short tube that carries urine from the bladder). The Bartholin glands are found just inside the opening of the vagina -- one on each side. These glands produce a mucus-like fluid that acts as a lubricant during sex.

At the front of the vagina, the labia minora meet to form a fold or small hood of skin called the *prepuce*. The *clitoris* is beneath the prepuce. The clitoris is an approximately ¾-inch structure of highly sensitive tissue that becomes swollen with blood during sexual stimulation. The labia minora also meet at a place just beneath the vaginal opening, at the *fourchette*. Beyond the fourchette is the *anus*, the opening to the rectum. The space between the vagina and the anus is called the *perineum*.

Cancer of the vulva (also known as *vulvar cancer*) most often affects the inner edges of the labia majora or the labia minora. Cancer occurs on the clitoris or in the Bartholin glands less often.

Types of vulvar cancer

Squamous cell carcinomas

Most cancers of the vulva are *squamous cell carcinomas*. This type of cancer begins in squamous cells, the main type of skin cells. There are several subtypes of squamous cell carcinoma:

- The keratinizing type is most common, and usually develops in older women, and is not linked to infection with human papilloma virus (HPV) (HPV is discussed in the section “What are the risk factors for vulvar cancer?”).
- Basaloid and warty types are less common, and are the kinds more often found in younger women with HPV infections.
- .Verrucous carcinoma is an uncommon subtype that is important to recognize because it is slow-growing and tends to have a good prognosis (outlook). This cancer looks like a large wart and a biopsy is needed to determine it is not a benign (non-cancerous) growth.

Adenocarcinoma

Cancer that begins in gland cells is called *adenocarcinoma*. About 8 of every 100 vulvar cancers are adenocarcinomas. Vulvar adenocarcinomas most often start in cells of the Bartholin glands. These glands are found just inside the opening of the vagina. A Bartholin gland cancer is easily mistaken for a cyst (accumulation of fluid in the gland), so a delay in accurate diagnosis is common. Most Bartholin gland cancers are adenocarcinomas. Adenocarcinomas can also form in the sweat glands of the vulvar skin.

Paget disease of the vulva is a condition in which adenocarcinoma cells are found in the top layer of the vulvar skin. Up to 25% of patients with vulvar Paget disease also have an invasive vulvar adenocarcinoma (in a Bartholin gland or sweat gland). In the remaining patients, the cancer cells are found only in the skin's top layer and have not grown into the tissues below.

Melanoma

Melanomas are cancers that develop from the pigment-producing cells that give skin color. They are much more common on sun-exposed areas of the skin, but can start in other areas, such as the vulva. Vulvar melanomas are rare, making up about 6 of every 100 vulvar cancers. More information about melanoma can be found in our document *Melanoma Skin Cancer*.

Sarcoma

A sarcoma is a cancer that begins in the cells of bones, muscles, or connective tissue. Less than 2 of every 100 vulvar cancers are *sarcomas*. Unlike other cancers of the vulva, vulvar sarcomas can occur in females at any age, including in childhood.

Basal cell carcinoma

Basal cell carcinoma, the most common type of skin cancer, is more often found on sun-exposed areas of the skin. It occurs very rarely on the vulva. For more information on this type of cancer, see our document *Skin Cancer: Basal and Squamous Cell*.

What are the key statistics about vulvar cancer?

In the United States, vulvar cancer accounts for about 4% of cancers of the female reproductive organs and 0.6% of all cancers in women. In the United States, women have a 1 in 333 chance of developing vulvar cancer at some point during their life.

The American Cancer Society's estimates for vulvar cancer in the United States for 2015 are:

- About 5,150 cancers of the vulva will be diagnosed
- About 1,080 women will die of this cancer.

What are the risk factors for vulvar cancer?

A risk factor is anything that changes a person's chance of getting a disease such as cancer. Different cancers have different risk factors. For example, exposing skin to strong sunlight is a risk factor for skin cancer. Smoking is a risk factor for many cancers.

There are different kinds of risk factors. Some, such as your age or race, can’t be changed. Others may be related to personal choices such as smoking, drinking, or diet. Some factors influence risk more than others. But risk factors don't tell us everything. Having a risk factor, or even several, does not mean that a person will get the disease. Also, not having any risk factors doesn't mean that you won't get it, either.

Although several risk factors increase the odds of developing vulvar cancer, most women with these risks do not develop it. And some women who don’t have any apparent risk factors develop vulvar cancer. When a woman develops vulvar cancer, it is usually not possible to say with certainty that a particular risk factor was the cause.

Age

The risk of vulvar cancer goes up as women age. Less than 20% of cases are in women younger than age 50, and more than half occur in women over age 70. The average age of women diagnosed with invasive vulvar cancer is 70, whereas women diagnosed with non-invasive vulvar cancer average about 20 years younger.

Human papilloma virus

Human papilloma virus (HPV) is a group of more than 150 types of viruses. They are called papilloma viruses because some of them cause a type of growth called a *papilloma*. Papillomas — more commonly known as warts — are not cancers. Different HPV types can cause different types of warts in different parts of the body. Some types cause common warts on the hands and feet. Other types tend to cause warts on the lips or tongue.

Certain HPV types can infect the outer female and male genital organs and the anal area, causing raised, bumpy warts. These warts may barely be visible or they may be several inches across. The medical term for genital warts is *condyloma acuminatum*. 2 types of HPV, HPV 6 and HPV 11, cause most cases of genital warts. These 2 types are seldom linked to cancer, and so are called *low-risk* types of HPV.

Other HPV types have been linked with cancers of the cervix and vulva in women, cancer of the penis in men, and cancers of the anus and throat (in men and women). These are known as *high-risk* types of HPV and include HPV 16, HPV 18, HPV 31, as well as others. Infection with a high-risk HPV may produce no visible signs until pre-cancerous changes or cancer develops.

HPV can be passed from one person to another during skin-to-skin contact. One way HPV is spread is through sex, including vaginal and anal intercourse and even oral sex.

More than half of all vulvar cancers are linked to infection with the high-risk HPV types. HPV linked vulvar cancer is more common in younger women and is seen less often in older women. Some doctors think there are 2 kinds of vulvar cancer. One kind is associated with HPV infection and tends to occur in younger women. The other is not associated with HPV infection, is more often found in older women, and may develop from a precursor lesion called *differentiated vulvar intraepithelial neoplasia* (discussed below).

Vaccines have been developed to help prevent infection with some types of HPV. Right now, 2 different HPV vaccines have been approved for use in the United States by the Food and Drug Administration (FDA): Gardasil® and Cervarix®. These are discussed in more detail later in this document.

For more about HPV, see our document *HPV and HPV Testing*.

Smoking

Smoking exposes people to many cancer-causing chemicals that affect more than their lungs. These harmful substances can be absorbed into the lining of the lungs and spread throughout the body. Smoking increases the risk of developing vulvar cancer. Among women who have a history of HPV infection, smoking further increases the risk of developing vulvar cancer. If women are infected with a high-risk HPV, they have a much higher risk of developing vulvar cancer if they smoke.

HIV infection

Human immunodeficiency virus (HIV) causes acquired immunodeficiency syndrome (AIDS). Because this virus damages the immune system, it makes women more likely to get and to stay infected with HPV. This could increase the risk of vulvar pre-cancer and cancer. Scientists also believe that the immune system plays a role in destroying cancer cells and slowing their growth and spread.

Vulvar intraepithelial neoplasia (VIN)

Squamous cell carcinoma of the vulva usually forms slowly over many years. Pre-cancerous changes often occur first and can last for several years. The medical term most often used for this pre-cancerous condition is *vulvar intraepithelial neoplasia* (VIN). "Intraepithelial" means that the abnormal cells are only found in the surface layer of the vulvar skin (epithelium).

VIN is typed by how the lesions and cells look: *usual-type VIN* and *differentiated-type VIN*.. It is sometimes graded VIN2 and VIN3, with the number 3 indicating furthest progression toward a true cancer. However, many doctors use only one grade of VIN.

- Usual-type VIN occurs in younger women and is caused by HPV infection. When usual-type VIN changes into invasive squamous cell cancer, it becomes the basaloid or warty subtypes.
- Differentiated-type VIN tends to occur in older women and is not linked to HPV infection. It can progress to the keratinizing subtype of invasive squamous cell cancer.

In the past, the term *dysplasia* was used instead of VIN, but this term is used much less often now. When talking about dysplasia, there is also a range of increasing progress toward cancer -- first, mild dysplasia; next, moderate dysplasia; then severe dysplasia; and, finally, *carcinoma in situ*.

Although women with VIN have an increased risk of developing invasive vulvar cancer, most cases of VIN never progress to cancer. Still, since it is not possible to tell which cases will become cancers, treatment or close medical follow-up is needed.

The risk of progression to cancer seems to be highest with VIN 3 and lower with VIN2. This risk can be altered with treatment. In one study, 88% of untreated VIN3 progressed to cancer, but of the women who were treated, only 4% developed vulvar cancer.

In the past, cases of VIN were included in the broad category of disorders known as *vulvar dystrophy*. Since this category included a wide variety of other diseases, most of which are not pre-cancerous, most doctors no longer use this term.

Lichen sclerosus

This disorder, also called *lichen sclerosus et atrophicus* (LSA), causes the vulvar skin to become very thin and itchy. The risk of vulvar cancer appears to be slightly increased by LSA, with about 4% of women having LSA later developing vulvar cancer.

Other genital cancers

Women with cervical cancer also have a higher risk of vulvar cancer. This is probably because these cancers share certain risk factors. The same HPV types that are linked to cervical cancer are also linked to vulvar cancer. Smoking is also linked to a higher risk of both cervical and vulvar cancers.

Melanoma or atypical moles

Women who have had melanoma or dysplastic nevi (atypical moles) in other places have an increased risk of developing a melanoma on the vulva. A family history of melanoma also leads to an increased risk.

Do we know what causes vulvar cancer?

Several risk factors for cancer of the vulva have been identified, and we are beginning to understand how these factors can cause cells in the vulva to become cancerous.

Researchers have made a lot of progress in understanding how certain changes in DNA can cause normal cells to become cancerous. DNA is the chemical that carries the instructions for nearly everything our cells do. We usually look like our parents because they are the source of our DNA. However, DNA affects more than our outward appearance. Some genes (parts of our DNA) contain instructions for controlling when our cells grow and divide.

Certain genes that promote cell division are called *oncogenes*. Others that slow down cell division or cause cells to die at the right time are called *tumor suppressor genes*. Cancers can be caused by DNA mutations (defects) that turn on oncogenes or turn off tumor suppressor genes. Usually DNA mutations related to cancers of the vulva occur during life rather than having been inherited before birth. Acquired mutations may result from cancer-causing chemicals in tobacco smoke. Sometimes they occur for no apparent reason. For more on genes and cancer, see our document *Oncogenes, Tumor Suppressor Genes, and Cancer*.

Studies suggest that squamous cell cancer of the vulva (the most common type) can develop in at least 2 ways. In up to half of cases, human papilloma virus (HPV) infection appears to have an important role. Vulvar cancers associated with HPV infection (the basaloid and warty subtypes) seem to have certain distinctive features. They are often found along with several other areas of vulvar intraepithelial neoplasia (VIN). The women who have these cancers tend to be younger and are often smokers.

The second process by which vulvar cancers develop does not involve HPV infection. Vulvar cancers not linked to HPV infection (the keratinizing subtype) are usually diagnosed in older women (over age 55). These women may have lichen sclerosis and may also have the differentiated type of VIN. DNA tests from vulvar cancers in older women rarely show HPV infection, but often show mutations of the *p53* tumor suppressor gene. The *p53* gene is important in preventing cells from becoming cancerous. When this gene has undergone mutation, it is easier for cancer to develop. Younger vulvar cancer patients with HPV infection rarely have p53 mutations.

These discoveries have not yet affected treatment. But they may help in finding ways to prevent cancer of the vulva and at some point might lead to changes in treatment.

Because vulvar melanomas and adenocarcinomas are so rare, much less is known about how they develop.

Can vulvar cancer be prevented?

The risk of vulvar cancer can be lowered by avoiding certain risk factors and by having pre-cancerous conditions treated before an invasive cancer develops. Taking these steps cannot guarantee that all vulvar cancers are prevented, but can greatly reduce your chances of developing vulvar cancer.

Avoid HPV infection

Infection with human papilloma virus (HPV) is a risk factor for vulvar cancer. In women, genital HPV infections occur mainly at younger ages and are less common in women over 30. The reason for this is not clear.

HPV is passed from one person to another during skin-to-skin contact with an infected area of the body. HPV can be spread during sex -- including vaginal intercourse, anal intercourse, and oral sex -- but sex doesn't have to occur for the infection to spread. All that is needed is skin-to-skin contact with an area of the body infected with HPV. The virus can be spread through genital-to-genital contact. It is even possible for a genital infection to spread through hand-to-genital contact.

An HPV infection also seems to be able to be spread from one part of the body to another. This means that an infection may start in the cervix and then spread to the vagina and vulva.

It can be very hard to avoid being exposed to HPV. It might be possible to prevent genital HPV infection by not letting others have contact with your anal or genital area, but even then there could be other ways to become infected that aren’t yet clear. For example, a recent study found HPV on the surface of sex toys, so sharing sex toys might spread HPV.

Infection with HPV is common, and in most cases your body is able to clear the infection on its own. But in some cases, the infection does not go away and becomes chronic. Chronic infection, especially with high-risk HPV types, can eventually cause certain cancers, including vulvar cancer.

Certain types of sexual behavior increase a woman's risk of getting a genital HPV infection, such as having sex at an early age and having many sexual partners. Although women who have had many sexual partners are more likely to get infected with HPV, a woman who has had only one sexual partner can still get infected. This is more likely if she has a partner who has had many sex partners or if her partner is an uncircumcised male.

Delaying sex until you are older can help you avoid HPV. It also helps to limit your number of sexual partners and to avoid having sex with someone who has had many other sexual partners.

A person can be infected with HPV for years and not have any symptoms, so the absence of visible warts cannot be used to tell if someone has HPV. Even when someone doesn't have warts (or any other symptom), he (or she) can still be infected with HPV and pass the virus to somebody else.

HPV in men

The 2 main factors influencing the risk of genital HPV infection in men are circumcision and the number of sexual partners. Men who are circumcised (have had the foreskin of the penis removed) have a lower chance of becoming and staying infected with HPV. Men who have **not** been circumcised are more likely to be infected with HPV and pass it on to their partners. The reasons for this are unclear. It may be that after circumcision the skin on the glans (of the penis) goes through changes that make it more resistant to HPV infection. Another theory is that the surface of the foreskin (which is removed by circumcision) is more easily infected by HPV. Still, circumcision does not completely protect against HPV infection -- men who are circumcised can still get HPV and pass it on to their partners.

The risk of a man being infected with HPV is also strongly linked to having many sexual partners (over a man's lifetime).

Condoms and HPV

Condoms ("rubbers") provide some protection against HPV, but they do not completely prevent infection. Men who use condoms are less likely to be infected with HPV and pass it on to their female partners. One study found that when condoms are used correctly every time sex occurs, they can lower the HPV infection rate in women by about 70%. Condoms cannot protect completely because they don't cover every possible HPV-infected area of the body, such as the skin on the genital or anal area. Still, condoms do provide some protection against HPV, and they also protect against HIV and some other sexually transmitted diseases. Condoms (when used by the male partner) also seem to help genital HPV infections clear (go away) faster in both women and men.

Get vaccinated against HPV

Vaccines are available that protect against certain HPV infections. All of them protect against infection with HPV subtypes 16 and 18. Some can also protect against infections with other HPV subtypes, including some types that cause anal and genital warts.

These vaccines can only be used to prevent HPV infection --they do not help treat an existing infection. To be most effective, the vaccine should be given before a person becomes exposed to HPV (such as through sexual activity).

All of these vaccines can help prevent cervical cancer and pre-cancer. At this time though, only 2 of the HPV vaccines available, Gardasil and Gardasil 9, are approved to prevent vulvar cancers and pre-cancers. They are also approved to help prevent anal and genital warts, as well as other cancers.

More HPV vaccines are being developed and tested.

For more information, see *HPV Vaccines*.

Don’t smoke

Not smoking is another way to lower the risk for vulvar cancer. Women who don't smoke are also less likely to develop a number of other cancers, like those of the lungs, mouth, throat, bladder, kidneys, and several other organs.

Find and treat pre-cancerous conditions

Pre-cancerous vulvar conditions that are not causing any symptoms can be found by regular gynecologic checkups. It is also important to see your health care provider if any problems come up between checkups. Symptoms such as vulvar itching, rashes, moles, or lumps that don't go away could be caused by vulvar pre-cancer and should be checked out. If vulvar intraepithelial neoplasia (VIN) is found, treating it might help prevent invasive squamous cell vulvar cancer. Also, some vulvar melanomas can be prevented by removing atypical moles.

The vulva is examined at the same time a woman has a pelvic examination. Cervical cancer screening with a Pap test (sometimes combined with a HPV test) is often done at the same time. Neither the Pap test nor the HPV test is used to screen for vulvar cancer. The purpose of these tests is to find cervical cancers and pre-cancers early. For more information about these tests and the American Cancer Society guidelines for the early detection of cervical cancer, see our documents *Cervical Cancer*, and *Cervical Cancer: Prevention and Early Detection.*

How Pap tests and pelvic examinations are done

First, the skin of the outer lips (labia majora) and inner lips (labia minora) is examined for any visible abnormalities. The health care professional then places a speculum inside the vagina. A speculum is a metal or plastic instrument that keeps the vagina open so that the cervix can be seen clearly. Next, using a small spatula, a sample of cells and mucus is lightly scraped from the exocervix (the surface of the cervix that is closest to the vagina). A small brush or a cotton-tipped swab is then inserted into the cervical opening to take a

sample from the endocervix (the inside part of the cervix that is closest to the body of the uterus). Then, the speculum is removed. The doctor then will check the organs of the pelvis by inserting 1 or 2 gloved fingers of one hand into the vagina while he or she palpates (feels) the lower abdomen, just above the pubic bone, with the other. The doctor may do a rectal exam at this time also. It is very important to know that a Pap test is not always done when a pelvic exam is done, so if you are uncertain you should ask if one was done.

Self-exam of the vulva

For most women, the best way to find VIN and vulvar cancer is to report any signs and symptoms to their health care provider and have a yearly well-woman exam. If you have an increased risk of vulvar cancer, you may also want to check your vulva regularly to look for any of the signs of vulvar cancer. This is known as self-examination. Some women choose to examine themselves monthly using a mirror. This can allow you to become aware of any changes in the skin of your vulva. If you do this, look for any areas that are white, darkly pigmented, or red and irritated. You should also note any new growths, nodules, bumps, or ulcers (open sores). Report any of these to a doctor, since they could indicate a vulvar cancer or pre-cancer.

Can vulvar cancer be found early?

Having pelvic exams and knowing any signs and symptoms of vulvar cancer greatly improve the chances of early detection and successful treatment. If you have any of the problems discussed in the next section, you should see a doctor. If the doctor finds anything abnormal during a pelvic examination, you may need more tests to figure out what is wrong. This may mean referral to a gynecologist (specialist in problems of the female genital system).

Knowing what to look for can sometimes help with early detection, but it is even better not to wait until you notice symptoms. Get regular well-women exams.

There is no standard screening for this disease.

Signs and symptoms of vulvar cancers and pre-cancers

Symptoms depend on whether it is a cancer or pre-cancer and what kind of cancer it is.

Vulvar intraepithelial neoplasia

Most women with vulvar intraepithelial neoplasia (VIN) have no symptoms at all. When a woman with VIN does have a symptom, it is most often itching that does not go away

or get better. An area of VIN may look different than normal vulvar skin. It is often thicker and lighter than the normal skin around it. However, an area of VIN can also appear red, pink, or darker than the surrounding skin.

Because these changes are often caused by other conditions that are not pre-cancerous, some women don't realize that they might have a serious condition. Some try to treat the problem themselves with over-the-counter remedies. Sometimes doctors might not even recognize the condition at first.

Invasive squamous cell cancer of the vulva

Almost all women with invasive vulvar cancers will have symptoms. These can include:

- An area on the vulva that looks different from normal – it could be lighter or darker than the normal skin around it, or look red or pink.
- A bump or lump, which could be red, pink, or white and could have a wart-like or raw surface or feel rough or thick
- Thickening of the skin of the vulva
- Itching
- Pain or burning
- Bleeding or discharge not related to the normal menstrual period
- Open sore (especially if it lasts for a month or more)

Verrucous carcinoma, a subtype of invasive squamous cell vulvar cancer, appears as cauliflower-like growths similar to genital warts.

These symptoms are more often caused by other, non-cancerous conditions. Still, if you have these symptoms, you should have them checked by a doctor or nurse.

Vulvar melanoma

Patients with vulvar, melanoma can have many of the same symptoms as other vulvar cancers, such as:

- A lump
- Itching
- Pain
- Bleeding or discharge

Most vulvar melanomas are black or dark brown, but they can be white, pink, red, or other colors. They can be found throughout the vulva, but most are in the area around the clitoris or on the labia majora or minora.

Vulvar melanomas can sometimes start in a mole, so a change in a mole that has been present for years can also indicate melanoma. The *ABCDE* rule can be used to help tell a normal mole from one that could be melanoma.

Asymmetry: One-half of the mole does not match the other.

Border irregularity: The edges of the mole are ragged or notched.

Color: The color over the mole is not the same. There may be differing shades of tan, brown, or black and sometimes patches of red, blue, or white.

Diameter: The mole is wider than 6 mm (about 1/4 inch).

Evolving: The mole is changing in size, shape, or color.

The most important sign of melanoma is a change in size, shape, or color of a mole. Still, not all melanomas fit the ABCDE rule.

If you have a mole that has changed, ask your doctor to check it out.

Bartholin gland cancer

A distinct mass (lump) on either side of the opening to the vagina can be the sign of a Bartholin gland carcinoma. More often, however, a lump in this area is from a Bartholin gland cyst, which is much more common (and is not a cancer).

Paget disease

Soreness and a red, scaly area are symptoms of Paget disease of the vulva.

How is vulvar cancer diagnosed?

Medical history and physical exam

The first step is for the doctor to take your complete medical history to check for risk factors and symptoms. Then your doctor will give you a complete physical exam, including a pelvic exam. He or she will feel your uterus, ovaries, cervix, and vagina for anything irregular. Your doctor will also use a speculum to look at your vagina and cervix and may do a Pap test.

Biopsy

Certain signs and symptoms might strongly suggest vulvar cancer, but many of them can be caused by conditions that aren't cancer. The only way to be certain that cancer is present is to do a biopsy. In this procedure, a small piece of tissue from the suspicious area is removed and examined under the microscope. A pathologist (a doctor specializing in diagnosing diseases by laboratory tests) will look at the tissue sample under a microscope to see if cancer or a pre-cancerous condition is present and, if so, what type it is.

Rarely, the doctor will paint the vulva with a dye (toluidine blue) to find all areas of abnormal vulvar skin and to select the best areas to biopsy. This dye causes skin with certain diseases -- including vulvar intraepithelial neoplasia (VIN) and vulvar cancer -- to turn blue.

The doctor might use a colposcope (an instrument with binocular magnifying lenses that stays outside the body) or a hand-held magnifying lens to select areas to biopsy. The vulva is treated with a dilute solution of acetic acid (like vinegar) that causes areas of VIN and cancer to turn white, making them easier to see through the colposcope. Examining the vulva with magnification is called *vulvoscopy*.

Once the abnormal areas are found, a numbing medicine (local anesthetic) is injected into the skin so you won’t feel pain. If the abnormal area is small, it may be completely removed (called an *excisional biopsy*) with a scalpel. Sometimes stitches are needed.

If the abnormal area is larger, a *punch biopsy* is used to take a small sample. The instrument used looks like a tiny apple corer and removes a small, cylindrical piece of skin 4 mm (about 1/6 inch) across. No stitches are usually needed after the punch biopsy. Depending on the results of the punch biopsy, additional surgery may be necessary.

To learn more about biopsies, see our document *Testing Biopsy and Cytology Specimens for Cancer*.

Further testing

If you have cancer, tests will be done to see how far it has spread. The results of your physical examination and certain diagnostic tests will be used to determine the size of the tumor, how deeply it has grown into tissues at the site where it originated, if it has grown into nearby organs, and if it has metastasized (spread to lymph nodes or distant organs). This is called *staging*. The stage of your cancer is the most important factor in selecting the right treatment plan. (See the section "How is vulvar cancer staged?" for more details)

If your biopsy shows that you have vulvar cancer, your health care professional will refer you to a *gynecologic oncologist*, a specialist in female reproductive system cancers. The specialist will also look at your complete personal and family medical history to learn about related risk factors and symptoms of vulvar cancer.

The doctor will perform a complete physical examination to evaluate your general state of health, paying special attention to the lymph nodes, particularly those in your groin region, to check for signs of cancer spread. Depending on the biopsy results, several more tests may be done to determine if the vulvar cancer has spread to other areas.

Cystoscopy

This examination uses a lighted tube to check the inside surface of the bladder. Some advanced cases of vulvar cancer can spread to the bladder, so any suspicious areas noted by this exam are removed for biopsy. This procedure can be done using a local anesthetic, but some patients may need general anesthesia. Your doctor will let you know what to expect before and after the procedure. This procedure was used more often in the past, but is no longer a standard part of the work-up of a woman with vulvar cancer.

Proctoscopy

This is a visual inspection of the rectum using a lighted tube. Some advanced cases of vulvar cancer can spread to the rectum. Any suspicious areas are biopsied. Proctoscopy was used more often in the past, but is no longer a standard part of the work-up of a woman with vulvar cancer.

Examination of the pelvis under anesthesia

Putting the patient under anesthesia permits a physician to do a more thorough exam that can better evaluate how much the cancer has spread to internal organs of the pelvis.

Imaging tests

Chest x-ray

A plain x-ray of your chest might be done to check for other health problems that might make certain treatments difficult to tolerate. This x-ray can be done in any outpatient setting.

Computed tomography (CT)

The computed tomography (CT) scan is an x-ray test that produces detailed cross-sectional images of your body. Instead of taking one picture, like a standard x-ray, a CT scanner takes many pictures as it rotates around you. A computer then combines these pictures into an image of a slice of your body. For vulvar cancer, a CT scan can help find enlarged lymph nodes that might contain areas of cancer spread. It can also be helpful to see if the cancer has spread to other organs.

A CT scanner has been described as a large donut, with a narrow table in the middle opening. You will need to lie still on the table while the scan is being done. CT scans take longer than regular x-rays, and you might feel a bit confined by the ring while the pictures are being taken.

Before the test, you may be asked to drink 1 to 2 pints of a liquid called *oral contrast*. This helps outline the intestine so that certain areas are not mistaken for tumors. You may also receive an IV line through which a different kind of contrast dye (IV contrast) is injected. This helps better outline structures such as blood vessels in your body.

The injection can cause some flushing (redness and warm feeling). A few people are allergic to the dye and get hives, or rarely, have more serious reactions like trouble breathing and low blood pressure. Be sure to tell the doctor if you have ever had a reaction to any contrast material used for x-rays.

CT scans are not often needed in vulvar cancer patients. They might be done in patients with large tumors or enlarged lymph nodes. They can also be helpful in deciding whether to do a sentinel lymph node procedure to check groin lymph nodes for cancer spread (this procedure is discussed in more detail in the "Surgery for vulvar cancer" section).

Magnetic resonance imaging (MRI)

Magnetic resonance imaging (MRI) scans use radio waves and strong magnets instead of x-rays to make images of the body. The energy from the radio waves is absorbed by the body and then released in a specific pattern formed by the type of tissue and by certain diseases. A computer translates the pattern into a very detailed image of parts of the body. Like a CT scanner, this produces cross sectional slices of the body. An MRI can also produce slices that are parallel with the length of your body. As with a CT scan, a contrast material might be used, but it is not needed as often.

MRI scans are more uncomfortable than CT scans. They take longer -- often up to an hour. You have to be placed inside tube-like equipment, which is confining and can upset people with claustrophobia (a fear of close spaces). If you have trouble with close spaces, let your doctor know before the MRI scan. Sometimes medicine can be given just before the scan to reduce anxiety. Another option is to use a special "open" MRI machine that is less confining and more comfortable for such people, the drawback being that the images from these machines are not as good. The machine also makes a buzzing or clanging noise that some people find disturbing. Some places will provide headphones with music to block this sound.

MRI images are particularly useful in examining pelvic tumors. They may often detect enlarged lymph nodes in the groin. They are also helpful in detecting cancer that has spread to the brain or spinal cord. However, they are rarely used in patients with early vulvar cancer.

Positron emission tomography (PET)

Positron emission tomography (PET) uses glucose (a form of sugar) that contains a low-level radioactive atom. Because cancer cells use glucose at a higher rate than normal cells, they absorb more of the radioactive sugar. The areas of radioactivity are detected with this test. You will be injected with the special glucose, and then about an hour later you will be moved onto a table in the PET scanner. You lie on the table for about 30 minutes while a special camera creates a picture of areas of radioactivity in the body. The picture is not finely detailed like a CT or MRI scan, but it provides helpful information about your body.

This test can be helpful for spotting collections of cancer cells, and seeing if the cancer has spread to lymph nodes. PET scans are also useful when your doctor thinks the cancer has spread, but doesn't know where (although they aren't useful for finding cancer spread in the brain). PET scans can be used instead of several different x-rays because they scan your whole body. Often, a machine that combines a PET scanner and a CT scanner (called a PET/CT) is used, which gives more information about areas of cancer and cancer spread.

For more information about scans and x-rays, see our document *Imaging (Radiology) Tests*.

How is vulvar cancer staged?

The FIGO/AJCC system for staging vulvar cancer

The systems used for staging most types of vulvar cancer -- the *FIGO* (International Federation of Gynecology and Obstetrics) system and the American Joint Committee on Cancer TNM staging system -- are very similar. They both classify vulvar cancer on the basis of: the extent of the tumor (T), whether the cancer has spread to lymph nodes (N) and whether it has spread to distant sites (M). The system described below is the most recent AJCC system, which went into effect January 2010. Any differences between the AJCC system and the FIGO system are explained in the text.

These systems are not used to stage vulvar melanoma, which is staged like melanoma of the skin. Information about melanoma staging can be found in our document *Melanoma Skin Cancer*.

Tumor extent (T)

Tis: The cancer is not growing into the underlying tissues. This stage, also known as *carcinoma in situ*, is not included in the FIGO system.

T1: The cancer is growing only in the vulva or perineum

- **T1a:** The cancer has grown no more than 1 mm into underlying tissue (stroma) and is 2 cm or smaller in size. (about 0.8 inches).
- **T1b:** The cancer is either more than 2 cm or it has grown more than 1 mm into underlying tissue (stroma).

T2: The tumor can be any size. The cancer is growing into the anus or the lower third of the vagina or urethra (the tube that drains urine from the bladder). (This is called stage 2/3 in the FIGO system)

T3: The tumor can be any size. The cancer is growing into the upper urethra, bladder or rectum or into the pubic bone. (This is called stage 4 in the FIGO system)

Lymph node spread of cancer (N)

N0: No lymph node spread

N1: The cancer has spread to 1 or 2 lymph nodes in the groin with the following features:

- **N1a:** The cancer has spread to 1 or 2 lymph nodes and the areas of cancer spread are both less than 5 mm (about 1/5th of an inch) in size
- **N1b:** The cancer has spread to one lymph node and the area of cancer spread is 5 mm or greater

N2: The cancer has spread to groin lymph nodes with the following features:

- **N2a:** The cancer has spread to 3 or more lymph nodes, but each area of spread is less than 5 mm
- **N2b:** The cancer has spread to 2 or more lymph nodes with each area of spread 5 mm or greater
- **N2c:** The cancer has spread to lymph nodes and has started growing through the outer covering of at least one of the lymph nodes (called extracapsular spread)

N3: The cancer has spread to the lymph nodes causing open sores (*ulceration*) or causing the lymph node to be stuck (*fixed*) to the tissue below it.

Distant spread of cancer (M)

M0: No distant spread

M1: The cancer has spread to distant sites (includes spread to pelvic lymph nodes)

Stage grouping

The grouping of T, N, and M determines the stage:

Stage 0 (Tis, N0, M0): This is a very early cancer found on the surface of the skin of the vulva only. It is also known as *carcinoma in situ* and as *Bowen disease*. This stage is not included in the FIGO system.

Stage I (T1, N0, M0): The cancer is in the vulva or the perineum (the space between the rectum and the vagina) or both. The tumor has not spread to lymph nodes or distant sites.

Stage IA (T1a, N0, M0): These are stage I cancers with tumors that are 2 cm or less that have grown into the underlying tissue no deeper than 1 mm (about 1/25 inch).

Stage IB (T1b, N0, M0): These are stage I cancers that have invaded deeper than 1 mm and/or are larger than 2 cm.

Stage II (T2, N0, M0): The cancer has grown outside the vulva or perineum to the anus or lower third of the vagina or urethra (T2). It has not spread to lymph nodes (N0) or distant sites (M0). In FIGO, this grouping is T2/T3, N0, M0, but it is still stage II.

Stage IIIA (T1 or T2, N1a or N1b, M0): Cancer is in the vulva or perineum or both (T1) and may be growing into the anus, lower vagina, or lower urethra (T2). Either it has spread to a single nearby lymph node with the area of cancer spread 5 mm or greater in size (N1a); OR it has spread to 1 or 2 nearby lymph nodes with both areas of cancer spread less than 5 mm in size (N1b). It has not spread to distant sites (M0). In FIGO, this stage is also IIIA, but it is split into IIIAi and IIIAii

- **Stage IIIAi (T1 or T2, N1a, M0)**: The cancer is in the vulva or perineum and may be any size and growing into the anus, lower vagina, or lower urethra (T1 or T2). It has spread to a single lymph node with the area of spread 5 mm or greater in size (N1a). It has not spread to distant sites (M0).

- **Stage IIIAii (T1 or T2, N1b, M0)**: The cancer is in the vulva or perineum and may be any size and growing into the anus, lower vagina, or lower urethra (T1 or T2). It has spread to 1 or 2 lymph nodes with the areas of cancer spread less than 5 mm in size (N1b). It has not spread to distant sites (M0).

Stage IIIB (T1 or T2, N2a or N2b, M0): Cancer is in the vulva or perineum or both (T1) and may be growing into the anus, vagina, or lower urethra (T2). Either, the cancer has spread to 3 or more nearby lymph nodes, with all areas of cancer spread less than 5 mm in size (N2a); OR the cancer has spread to 2 or more lymph nodes with each area of spread 5 mm or greater in size (N2b). The cancer has not spread to distant sites (M0). In FIGO, this stage is also IIIB, but it is split into IIIBi and IIIBii.

- **Stage IIIBi (T1 or T2, N2a, M0)**: The cancer is in the vulva or perineum and may be any size and growing into the anus, lower vagina, or lower urethra (T1 or T2). The

cancer has spread to 3 or more nearby lymph nodes, with all areas of cancer spread less than 5 mm in size (N2a). It has not spread to distant sites (M0).

- **Stage IIIBii (T1 or T2, N2b, M0**): The cancer is in the vulva or perineum and may be any size and growing into the anus, lower vagina, or lower urethra (T1 or T2). The cancer has spread to 2 or more lymph nodes with each area of spread 5 mm or greater in size (N2b). It has not spread to distant sites (M0).

Stage IIIC (T1 or T2, N2c, M0): Cancer is in the vulva or perineum or both (T1) and may be growing into the anus, lower vagina, or lower urethra (T2). The cancer has spread to nearby lymph nodes and has started growing through the outer covering of at least one of the lymph nodes (called extracapsular spread; N2c). The cancer has not spread to distant sites (M0). In FIGO, this stage is also called IIIC.

Stage IVA: Either of the following:

T1 or T2, N3, M0: Cancer is in the vulva or perineum or both (T1) and may be growing into the anus, vagina, or lower urethra (T2). Cancer spread to nearby lymph nodes has caused them to be stuck (fixed) to the underlying tissue or caused open sores (ulceration) (N3). It has not spread to distant sites. In FIGO, this stage is also called IVA.

OR

T3, any N, M0: The cancer has spread beyond nearby tissues to the bladder, rectum, pelvic bone, or upper part of the urethra (T3). It may or may not have spread to nearby lymph nodes (any N). It has not spread to distant sites (M0). In FIGO, this stage is also IVA.

Stage IVB (any T, any N, M1): Cancer has spread to distant organs or lymph nodes (M1). This is the most advanced stage of cancer. In FIGO, this stage is also IVB.

Survival by stage of vulvar cancer

Survival rates are often used by doctors as a standard way of discussing a person's prognosis (outlook). Some patients with cancer may want to know the survival statistics for people in similar situations, while others may not find the numbers helpful, or may even not want to know them. If you decide that you don’t want to know them, stop reading here and skip to the next section.

The 5-year survival rate refers to the percentage of patients who live *at least 5 years* after their cancer is diagnosed. Five-year survival rates are used to produce a standard way of discussing prognosis. Of course, many people live much longer than 5 years.

Relative survival rates assume that people will die of other causes and compare the observed survival with that expected for people without vulvar cancer. This is a more accurate way to describe the outlook for patients with a particular type and stage of cancer.

Keep in mind that 5-year survival rates are based on patients diagnosed and initially treated more than 5 years ago. Improvements in treatment often result in a more favorable outlook for women more recently diagnosed with vulvar cancer

Survival rates are often based on previous outcomes of large numbers of people who had the disease, but they cannot predict what will happen in any particular person's case. Many other factors may affect a person's outlook, such as the type of vulvar cancer, the patient's age and general health, the treatment received, and how well the cancer responds to treatment. Your doctor can tell you how the numbers below may apply to you and your particular situation.

The numbers below come from the National Cancer Institute's SEER program. SEER does not list survival rates by FIGO (or AJCC) stage. Instead, it divides patients into 3 summary stages:

- Local: The cancer is only in the vulva, without spread to lymph nodes or nearby tissues. This is like stages I and II.
- Regional:The cancer has spread to nearby lymph nodes or tissues, but hasn't spread to distant organs. This is like stages III and IVA
- Distant: The cancer has spread to distant organs or tissues. This is like stage IVB.

Stage	**Relative 5-Year Survival Rate**
Local	86%
Regional	54%
Distant	16%

How is vulvar cancer treated?

This information represents the views of the doctors and nurses serving on the American Cancer Society's Cancer Information Database Editorial Board. These views are based on their interpretation of studies published in medical journals, as well as their own professional experience.

The treatment information in this document is not official policy of the Society and is not intended as medical advice to replace the expertise and judgment of your cancer care team. It is intended to help you and your family make informed decisions, together with your doctor.

Your doctor may have reasons for suggesting a treatment plan different from these general treatment options. Don't hesitate to ask him or her questions about your treatment options.

General treatment information

After the stage of your vulvar cancer has been established, your cancer care team will recommend a treatment strategy. Think about your options without feeling rushed. If there is anything you do not understand, ask to have it explained again.

The choice of treatment depends largely on the stage of the disease at the time of diagnosis, but other factors can play a part in choosing the best treatment plan, such as your age, your general health, your individual circumstances, and your preferences. Be sure you understand all the risks and side effects of the various therapies before making a decision.

You may want to get a second opinion. This can provide more information and help you feel confident about the treatment plan you choose. Some insurance companies require a second opinion before they will pay for treatments.

Depending on the type and stage of your vulvar cancer, you may need more than one type of treatment. Doctors on your cancer treatment team may include:

- A gynecologist: a doctor who specializes in diseases of the female reproductive tract
- A gynecologic oncologist: a doctor who specializes in treating cancers of the female reproductive system (including surgery and chemotherapy)
- A radiation oncologist: a doctor who uses radiation to treat cancer
- A medical oncologist: a doctor who uses chemotherapy and other medicines to treat cancer

Many other specialists may be involved in your care as well, including nurse practitioners, nurses, psychologists, social workers, rehabilitation specialists, and other health professionals.

The 3 main types of treatment used for patients with vulvar cancer are

- Surgery
- Radiation therapy
- Chemotherapy

Vulvar pre-cancers (vulvar intraepithelial neoplasia or VIN) can also be treated with *topical therapy*.

For information about some of the most common approaches used based on the type of vulvar cancer, see the sections “Treatment options for squamous cell vulvar cancer by stage,” “Treatment of vulvar adenocarcinoma,” and “Treatment of vulvar melanoma.”

It is important to discuss all of your treatment options, including their goals and possible side effects, with your doctors to help make the decision that best fits your needs.

It’s also very important to ask questions if there is anything you’re not sure about. You can find some good questions to ask in the section “What should you ask your doctor about vulvar cancer?”

Surgery for vulvar cancer

Choosing the best surgical treatment for each woman means balancing the importance of maintaining sexual functioning with the need to remove all the cancer. In the past, surgeons removing a vulvar cancer also took out a large amount of surrounding normal tissue and often nearby lymph nodes as well, regardless of the stage of the cancer. They did this because they wanted to be sure that no undetected cancer cells remained. Such extensive surgery resulted in a good chance of cure, but it was deforming and impaired the woman's sexual function if the clitoris had been removed. The removal of all the lymph nodes in the groin often led to disabling swelling of the leg (lymphedema) on that side.

Today, the importance of quality of life and sexuality is well recognized. It has also been established that, when cancer is detected early, it is not necessary to remove so much surrounding healthy tissue to achieve a cure. In addition, the sentinel node biopsy procedure is an alternative to removing many lymph nodes if the cancer has not spread (this is discussed further on). When cancer is more advanced, an extensive procedure may be necessary. Radiation can be combined with chemotherapy and surgery to kill more cancer cells in advanced cancers.

The following types of surgery are listed in order of how much tissue is removed (from least to most):

Laser surgery

A focused laser beam vaporizes (burns off) the layer of vulvar skin containing abnormal cells. Laser surgery is used as a treatment for VIN (vulvar pre-cancer). It is not used to treat invasive cancer.

Excision

The cancer and a margin of normal-appearing skin (usually about ½ inch) around it are excised (cut out). This is sometimes called *wide local excision*. If extensive (a lot of tissue is removed), it may be called a *simple partial vulvectomy*.

Vulvectomy

In this type of operation, all or part of the vulva is removed.

- A *skinning vulvectomy* means only the top layer of skin affected by the cancer is removed. Although this is an option for treating extensive VIN, this operation is rarely done.
- In a *simple vulvectomy*, the entire vulva is removed.
- A *radical vulvectomy* can be complete or partial. When part of the vulva, including the deep tissue, is removed, the operation is called a *partial radical vulvectomy*. In a *complete radical vulvectomy*, the entire vulva and deep tissues, including the clitoris, are removed. A complete radical vulvectomy is not often needed.

Sometimes these procedures remove a large area of skin from the vulva, requiring skin grafts from other parts of the body to cover the wound. However, most of the time the surgical wounds resulting from these procedures can be closed without grafts and still provide a very satisfactory appearance. If a skin graft is required, the gynecologic oncologist may do it. Otherwise, it may be done by a plastic/reconstructive surgeon after the gynecologic oncologist has done the vulvectomy.

Reconstructive surgery is available for women who have had more extensive surgery. A reconstructive surgeon will take a piece of skin and underlying fatty tissue and sew it into the area where the cancer was removed. Several sites in the body can be used, but it is complicated by the fact that the blood supply to the transplanted tissue needs to be kept intact. This is where a skillful surgeon is needed because the tissue must be moved without damaging the blood supply. If you are having this procedure, ask the surgeon to explain how it will be done, because there is no set way of doing it.

Pelvic exenteration

Pelvic exenteration is an extensive operation that when used to treat vulvar cancer includes vulvectomy and often removal of the pelvic lymph nodes, as well as removal of one or more of the following structures: the lower colon, rectum, bladder, uterus, cervix, and vagina. How much has to be removed depends on how far the cancer has spread.

If the bladder is removed, a new way to store and eliminate urine is needed. Usually a short segment of intestine is used to function as a new bladder. This may be connected to the abdominal wall so that urine is drained periodically when the woman places a catheter into a small opening (called a *urostomy*). Or urine may drain continuously into a small plastic bag attached to the front of the abdomen over the opening.

If the rectum and part of the colon are removed, a new way to eliminate solid waste will be needed. This is made by attaching the remaining intestine to the abdominal wall so that fecal material can pass through a small opening (called a *colostomy*) into a small plastic bag worn on the front of the abdomen. Sometimes it's possible to remove a piece of the colon and then reconnect it. In that case, the woman will not need bags or external appliances.

Inguinal lymph node dissection

Because vulvar cancer often spreads to lymph nodes in the groin, these may need to be removed. This procedure is called an *inguinal lymph node dissection*. Usually only lymph nodes on the same side as the cancer are removed. If the cancer is in or near the middle, then both sides may have to be done.

In the past, the incision (cut in the skin) that was used to remove the cancer in the vulva was made larger to remove the lymph nodes. Now, doctors prefer to remove the lymph nodes through a separate incision located about 1 to 2 cm (less than ½ to 1 inch) below and parallel to the groin crease. The incision is made fairly deep, down through membranes that cover the major inguinal vein and artery. This will expose most of the lymph nodes, which are then removed. A major vein, the saphenous vein, may or may not be closed off by the surgeon. Some surgeons will try to save it in an effort to reduce leg swelling (lymphedema) after surgery, but some doctors will not try to save the vein since the problem with swelling is mainly caused by the lymph node removal. After the surgery, a suction drain is placed into the incision and the wound is closed. The drain remains in place until it is not draining much fluid.

Sentinel lymph node biopsy

This is a newer procedure that can help some women avoid having a full inguinal node dissection. This procedure finds and removes the lymph nodes that drain the area where the cancer is. These lymph nodes are known as *sentinel lymph nodes* because cancer would be expected to spread to them first. The lymph nodes that are removed are then

looked at under the microscope to see if they contain cancer cells. If they do, then the remaining lymph nodes in this area need to be removed. If the sentinel nodes do not contain cancer cells, further lymph node surgery is not needed. This procedure can be used instead of an inguinal lymph node dissection for cancers that are fairly small (less than 4 cm) as long as there is no obvious lymph node spread.

To find the sentinel lymph node(s), a small amount of radioactive material and/or blue dye is injected into the tumor site on the day before surgery. The groin is scanned to identify the side (left or right) that picks up the radioactive material. This is the side that where the lymph nodes will be removed. During the surgery to remove the cancer, blue dye will be injected again into the tumor site. This allows the surgeon to find the sentinel node by its blue color and then remove it. Sometimes 2 or more lymph nodes turn blue and are removed.

If a lymph node near a vulvar cancer is abnormally large, a sentinel lymph node biopsy is usually not done. Instead, a fine needle aspiration (FNA) biopsy or surgical biopsy of that lymph node is done to check for cancer spread.

Complications and side effects of vulvar surgery

After vulvar surgery, women often feel discomfort if they wear tight slacks or jeans because the "padding" around the urethral opening and vaginal entrance is gone. The area around the vagina also looks very different.

Removal of wide areas of vulvar skin may result in problems with wound healing, wound infections, or failure of the skin graft to take. The more tissue removed, the greater the risk of these complications.

The urine stream might go to one side because tissue on one or both sides of the urethral opening has been removed.

Other complications of vulvar and groin node surgery include formation of fluid-filled cysts near the surgical wounds, blood clots that may travel to the lungs, urinary infections, and reduction of sexual desire or pleasure.

Lymphedema: Removal of groin lymph nodes (lymphadenectomy) can result in poor fluid drainage from the legs. This makes the fluid build up and leads to leg swelling that is severe and doesn’t go down at night. This is called *lymphedema*. The risk of this is higher if radiation is given after surgery. Information about lymphedema and how to manage it can be found in our document *Understanding Lymphedema (For Cancers Other Than Breast Cancer).*

Sexual impact of vulvectomy: Women often fear their partners will feel turned off by the scarring and loss of the outer genitals, especially during oral sex. Some women may be able to have surgery to rebuild the outer and inner lips of the genitals.

It may be difficult for women who have had a vulvectomy to reach orgasm. The outer genitals, especially the clitoris, are important in a woman's sexual pleasure. For many women, the vagina is just not as sensitive. Women may also notice numbness in their genital area after a radical vulvectomy, but feeling may return over the next few months.

When touching the area around the vagina, and especially the urethra, a light caress and the use of a lubricant can help prevent painful irritation. If scar tissue narrows the entrance to the vagina, penetration may be painful. Vaginal dilators can sometimes help stretch the opening. When scarring is severe, the surgeon can sometimes use skin grafts to widen the entrance. Sometimes, a special type of physical therapy called *pelvic floor therapy* may help.

Lymphedema resulting from removal of lymph nodes in the groin area can cause pain and fatigue. This also can be a problem during sex. A couple will need to use good communication to cope with such problems.

For more information about the sexual impact of cancer treatment, see our document *Sexuality for the Woman With Cancer*. For more general information about surgery as a cancer treatment, see *A Guide to Cancer Surgery*.

Radiation therapy for vulvar cancer

Radiation therapy uses high-energy rays (such as gamma rays or x-rays) and particles (such as electrons, protons, or neutrons) to kill cancer cells. In treating vulvar cancers, radiation is delivered from outside the body in a procedure that is much like having a diagnostic x-ray. This is called *external beam radiation therapy*. It is sometimes used along with chemotherapy to treat more advanced cancers to shrink them so they can be removed with surgery. This can sometimes allow the cancer to be removed with a less extensive surgery. Radiation alone may be used to treat lymph nodes in the groin and pelvis.

Common temporary side effects of radiation therapy to the pelvis include

- Tiredness
- Upset stomach, nausea, and vomiting
- Loose bowels or diarrhea
- Skin changes
- Low blood counts

These side effects tend to be worse when chemotherapy is given with radiation.

Tiredness can become severe a few weeks after treatment begins. Diarrhea, nausea, and vomiting from radiation can usually be controlled with medicines.

Skin changes are common in the area the radiation passes through to reach the cancer. This can range from mild, temporary redness to permanent discoloration. Radiation can cause the vulvar area to become sensitive and sore. The skin may release fluid, which can lead to infection, so the area exposed to radiation must be carefully cleaned and protected.

Radiation can also lead to low blood counts, causing anemia (low red blood cells) and leukopenia (low white blood cells). Low red blood cell counts can lead to feeling tired and short of breath. Low white blood cells can increase the risk of serious infection. The blood counts usually return to normal after radiation is stopped.

Women who receive radiation to the inguinal (groin) area after a lymph node dissection may have problems with the surgical wound site. It may open up or have trouble healing.

Radiation to the lymph nodes can lead to poor fluid drainage from the legs. The fluid can build up and lead to severe leg swelling that doesn't go down at night. This is called *lymphedema*. Information about lymphedema and how to manage it can be found in our document *Understanding Lymphedema (For Cancers Other Than Breast Cancer)*.

If you have side effects from radiation, tell your cancer care team. There are often ways to relieve them.

For more information about radiation as a treatment for cancer, see *Understanding Radiation Therapy: A Guide for Patients and Families*.

Chemotherapy for vulvar cancer

Chemotherapy (chemo) uses anti-cancer drugs that are usually given intravenously (into a vein), by mouth, or applied to the skin in other ways, such as in an ointment. Drugs taken by mouth or injected into a vein, called *systemic chemo*, enter the bloodstream and reach throughout the body, making this treatment potentially useful for cancer that has spread to distant sites.

Drugs most often used in treating vulvar cancer include cisplatin with or without fluorouracil (5-FU). Another chemo drug, mitomycin, may rarely be used. These may be combined with radiation. Different drugs are used to treat vulvar melanoma. Our document *Melanoma Skin Cancer* has more information about drug treatment for advanced melanomas.

The role of chemo in treating vulvar cancer remains to be determined. In more advanced disease, chemo might be given with radiation therapy before surgery. This combined treatment may shrink the tumor, making it easier to remove it with surgery. So far, the results of treating vulvar cancers that have spread to other organs with chemo have been disappointing.

Many of the drugs used in cancer chemo work by attacking cells that are rapidly dividing. This is helpful in killing cancer cells, but these drugs can also affect normal cells, leading to side effects. Side effects of chemo depend on the type of drugs, the amount taken, and the length of time you are treated. Common side effects of some of the drugs used to treat vulvar cancer include:

- Nausea and vomiting
- Temporary loss of hair
- Mouth or vaginal sores
- Changes in the menstrual cycle, premature menopause, and infertility (inability to become pregnant). Most women with vulvar cancer, however, have already gone through menopause.
- Diarrhea

Chemo often affects the blood-forming cells of the bone marrow, leading to low blood counts. This can cause:

- Increased chance of infections (due to low white blood cell count)
- Increased chance of bleeding and bruising (due to low blood platelet count)
- Tiredness (due to anemia, that is, low red blood cell count)

Other side effects can occur depending on what drug is used. Most side effects are temporary and stop when the treatment is over, but some chemo drugs can have long-lasting or even permanent effects. For example, cisplatin can cause nerve damage (called neuropathy). This can lead to numbness, tingling, or even pain in the hands and feet. It can also damage the kidneys. To lower the risk of kidney damage, the patient is given plenty of fluids intravenously (IV) before and after each dose.

Ask your cancer care team about the chemo drugs you will receive and what side effects you can expect. Also be sure to talk with them about any side effects you do have so that they can be treated. For example, you can be given medicine to reduce or prevent nausea and vomiting.

For more information about chemo and its side effects, see our document *A Guide to Chemotherapy*.

Topical therapy for vulvar pre-cancer

Topical therapy applies the drug directly onto the cancer. This is another way to treat vulvar intraepithelial neoplasia (VIN), but is not used to treat invasive vulvar cancer.

One choice is to apply the chemotherapy drug, fluorouracil (5-FU), directly to the skin of the vulva. This is called *topical chemotherapy*. Chemotherapy applied directly to the skin as an ointment will cause local irritation and peeling. This is normal and is part of the local destruction of cancer cells. Medicated ointments suggested by the health care team can help relieve the discomfort of this treatment. Topical chemotherapy for VIN is less effective than laser treatment or surgery.

A second drug that can be used topically is called imiquimod. This drug comes in a cream to be applied to the area of VIN. Imiquimod is not a chemotherapy drug. Instead, it acts by boosting the body's immune response to the area of abnormal tissue. This treatment has improved VIN, and in some women, it has made VIN go away completely.

Clinical trials for vulvar cancer

You may have had to make a lot of decisions since you've been told you have cancer. One of the most important decisions you will make is choosing which treatment is best for you. You may have heard about clinical trials being done for your type of cancer. Or maybe someone on your health care team has mentioned a clinical trial to you.

Clinical trials are carefully controlled research studies that are done with patients who volunteer for them. They are done to get a closer look at promising new treatments or procedures.

If you would like to take part in a clinical trial, you should start by asking your doctor if your clinic or hospital conducts clinical trials. You can also call our clinical trials matching service for a list of clinical trials that meet your medical needs. You can reach this service at 1-800-303-5691 or on our website at www.cancer.org/clinicaltrials. You can also get a list of current clinical trials by calling the National Cancer Institute's Cancer Information Service toll-free at 1-800-4-CANCER (1-800-422-6237) or by visiting the NCI clinical trials website at www.cancer.gov/clinicaltrials.

You must meet requirements to take part in any clinical trial. If you do meet them and qualify, though, it is still your decision whether or not to enter (enroll in) it.

Clinical trials are one way to get state-of-the art cancer treatment. In some cases they may be the only way to get access to newer treatments. They are also the only way for doctors to learn better methods to treat cancer. Still, they are not right for everyone.

You can get a lot more information on clinical trials in our document called *Clinical Trials: What You Need to Know*.

Complementary and alternative therapies for vulvar cancer

When you have cancer you are likely to hear about ways to treat your cancer or relieve symptoms that your doctor hasn't mentioned. Everyone from friends and family to

Internet groups and websites may offer ideas for what might help you. These methods can include vitamins, herbs, and special diets, or other methods such as acupuncture or massage, to name a few.

What exactly are complementary and alternative therapies?

Not everyone uses these terms the same way, and they are used to refer to many different methods, so it can be confusing. We use *complementary* to refer to treatments that are used *along with* your regular medical care. *Alternative* treatments are used *instead of* a doctor's medical treatment.

Complementary methods: Most complementary treatment methods are not offered as cures for cancer. Mainly, they are used to help you feel better. Some methods that are used along with regular treatment are meditation to reduce stress, acupuncture to help relieve pain, or peppermint tea to relieve nausea. Some complementary methods are known to help, while others have not been tested. Some have been proven not to be helpful, and a few have even been found harmful.

Alternative treatments: Alternative treatments may be offered as cancer cures. These treatments have not been proven safe and effective in clinical trials. Some of these methods may pose danger, or have life-threatening side effects. But the biggest danger in most cases is that you may lose the chance to be helped by standard medical treatment. Delays or interruptions in your medical treatments may give the cancer more time to grow and make it less likely that treatment will help.

Finding out more

It is easy to see why people with cancer think about alternative methods. You want to do all you can to fight the cancer, and the idea of a treatment with few or no side effects sounds great. Sometimes medical treatments like chemotherapy can be hard to take, or they may no longer be working. But the truth is that most of these alternative methods have not been tested and proven to work in treating cancer.

As you consider your options, here are 3 important steps you can take:

- Look for "red flags" that suggest fraud. Does the method promise to cure all or most cancers? Are you told not to have regular medical treatments? Is the treatment a "secret" that requires you to visit certain providers or travel to another country?
- Talk to your doctor or nurse about any method you are thinking about using.
- Contact us at 1-800-227-2345 to learn more about complementary and alternative methods.

The choice is yours

Decisions about how to treat or manage your cancer are always yours to make. If you want to use a non-standard treatment, learn all you can about the method and talk to your doctor about it. With good information and the support of your health care team, you may be able to safely use the methods that can help you while avoiding those that could be harmful.

Treatment options for squamous cell vulvar cancer by stage

The stage of a vulvar cancer is the most important factor in choosing treatment. However, other factors that affect this decision include the exact location of the cancer on the vulva, the type of cancer, your age, and your overall health.

Stage 0 (carcinoma in situ)

Treatment options for carcinoma in situ and for less advanced pre-cancerous changes (vulvar intraepithelial neoplasia, or VIN) are the same. If left untreated, nearly all will progress to invasive vulvar cancer. Surgery, such as laser surgery, wide local excision, or a skinning vulvectomy may be used, depending on the size and location of the cancer. A topical therapy such as fluorouracil (5-FU) ointment or imiquimod cream may be applied to the abnormal areas. Even if treated, stage 0 cancers may recur (come back) or new stage 0 cancers may form on other areas of the vulva, so good follow-up is important. The 5-year survival rate is nearly 100%, similar to pre-invasive skin cancers in other body sites.

Stage I

Treatment options depend on the size and depth of the cancer and whether the patient also has VIN. If the depth of invasion is 1 mm or less (stage IA) and there are no other areas of cancer or VIN, the cancer is surgically removed along with a 1 cm (less than half an inch) margin of the normal tissue around it.

For stage IB cancers, treatment may include a partial radical vulvectomy and inguinal lymph node dissection (removal of nearby groin lymph nodes). Sentinel lymph node biopsy may be done instead of the lymph node dissection.

Another option rarely used for cancers that are larger and quite extensive is a complete radical vulvectomy and removal of the groin lymph nodes.

If the lymph nodes are not removed because the patient is not healthy enough to withstand the surgery, radiation therapy may be given to the groin areas. If the lymph

nodes are enlarged, a needle biopsy may be done before treatment to see if the nodes contain cancer cells.

Patients who are not healthy enough to have any surgery may be treated with radiation therapy alone.

Stage II

Stage II cancers have spread to structures near the vulva, such as the anus, the lower third of the vagina, and/or the lower third of the urethra. One option for treatment is partial radical vulvectomy (removal of the tumor, nearby parts of the vulva, and other tissues containing cancer). Surgery may also include removal of the lymph nodes in the groin on both sides of the body (or sentinel node biopsies). Radiation therapy to the area of surgery may be needed if cancer cells are at or near the margins (edges of the tissue removed by surgery).

For women who are too sick or weak from other medical problems to have surgery, radiation (with or without chemotherapy) may be used as the main treatment.

Stage III

Stage III cancers have spread to nearby lymph nodes. Treatment may include surgery to remove the cancer (either a radical wide local incision or partial or complete radical vulvectomy) and lymph nodes in the groin. This may be followed by radiation therapy. Sometimes chemotherapy (chemo) with 5-FU or cisplatin (sometimes with mitomycin) is given along with the radiation to help it work better.

These cancers may also be treated with radiation (with or without chemo) first, followed by surgery to remove any remaining cancer. This is often done to try to preserve normal structures such as the vagina, urethra and anus.

Radiation and chemo (without surgery) may be used as the main treatment for patients who cannot have surgery due to underlying medical problems.

Stage IVA

These cancers have spread more extensively to organs and tissues in the pelvis, such as the rectum (above the anus), the bladder, the pelvic bone, the upper part of the vagina, and the upper part of the urethra. When treated with surgery, the goal is to remove as much of the cancer as possible. The extent of the surgery beyond a radical vulvectomy depends on what organs contain cancer cells. Pelvic exenteration is an option, although it is used rarely. This operation includes vulvectomy and removal of the pelvic lymph nodes plus removal of some of the following: the lower colon, rectum, bladder, uterus, cervix, and vagina.

The standard approach is to combine surgery, radiation, and chemo. Radiation therapy may be done before or after surgery. Chemo may also be given before surgery. Radiation and possibly chemo can also be given to women who cannot have surgery because of prior medical problems.

Stage IVA also includes T1 and T2 tumors with less severe nearby spread but extensive spread to nearby lymph nodes that has caused the lymph nodes to become fixed (stuck to the underlying tissue) or ulcerated (become open sores). These cancers are often treated with radical vulvectomy and removal of the groin lymph nodes. Radiation (often with chemo) may be given either before or after surgery.

Stage IVB

These cancers have spread to lymph nodes in the pelvis or to organs and tissues outside the pelvis (like the lungs or liver). Surgery is not expected to cure these cancers, but may be helpful in relieving symptoms of bowel or bladder blockages. Radiation may also be helpful in shrinking the cancer and improving symptoms. Chemo may also be an option, as is enrolling in a clinical trial.

Recurrent vulvar cancer

When cancer comes back after treatment, it is called *recurrent cancer*. Treatment options will depend on how soon the cancer comes back and whether the recurrence is *local* (in the vulva), *regional* (in nearby lymph nodes), or *distant* (has spread to organs such as the lungs or bones).

If the recurrence is local, it may still be possible to remove the cancer by surgery or by using combinations of chemo, radiation therapy, and surgery. Vulvar cancer that comes back locally more than 2 years after the initial treatment has a better prognosis (outlook) than cancers that recur sooner.

When the cancer has grown too large or spread too far to be surgically removed (is unresectable), chemo and/or radiation therapy may be used to help relieve symptoms such as pain caused by the cancer, or to shrink the tumor so that surgery may become an option. If treatment is given only to relieve pain or bleeding, it is called *palliative* (symptom relief) therapy.

It's very important to understand that palliative treatment is not expected to cure a cancer. Women with advanced vulvar cancer are encouraged to enter a clinical trial where they may receive new forms of therapy that may be helpful but are as yet unproven.

Treatment of vulvar adenocarcinoma

If Paget's disease is present and there is no associated invasive carcinoma, treatment is wide local excision or simple vulvectomy (see "Surgery for vulvar cancer"). If an invasive adenocarcinoma of a Bartholin gland or of vulvar skin sweat glands is present, a partial radical vulvectomy is recommended with removal of inguinal (groin) lymph nodes on one or both sides of the body, depending on the site of the primary tumor.

Advanced vulvar adenocarcinoma is often treated with chemotherapy or radiation.

Treatment of vulvar melanoma

Treatment options depend on how deeply the melanoma has grown into the skin of the vulva. If the depth is less than 0.75 millimeter, partial vulvectomy removing 1 to 2 cm (up to about ¾ inch) of normal tissue (margins) is the usual treatment (see "Surgery for vulvar cancer"). If the cancer has grown in deeper, more tissue may need to be removed. Radical vulvectomy may rarely be used when the lesion extensively involves the vulva.

Often, lymph nodes in the groin will be sampled or a sentinel node biopsy procedure will be done to fully stage the cancer. The stage helps predict the outlook for survival and is needed to decide if other treatment is needed.

If the melanoma has spread outside the vulva, other treatments may be needed. These are discussed in our document *Melanoma Skin Cancer*.

More treatment information about vulvar cancer

For more details on treatment options -- including some that may not be addressed in this document -- the National Cancer Institute (NCI) can be a good source of information.

The NCI provides treatment guidelines via its telephone information center (1-800-4-CANCER) and its website (www.cancer.gov). Detailed guidelines intended for use by cancer care professionals are also available on www.cancer.gov.

What should you ask your doctor about vulvar cancer?

It is important for you to have honest, open discussions with your cancer care team. They want to answer all of your questions, no matter how trivial you might think they are. Here are some questions to consider:

- What type of vulvar cancer do I have?
- Has my cancer spread beyond the vulva?

- What is the stage of my cancer and what does that mean?
- What treatments are appropriate for me? What do you recommend? Why?
- What should I do to be ready for treatment?
- What risks or side effects should I expect?
- Can anything be done to minimize my risks?
- Will I be able to have children after my treatment?
- Will I be able to enjoy normal sexual relations?
- What are the chances my cancer will recur (come back) with the treatments we have discussed?
- Should I follow a special diet?
- What is my expected prognosis, based on my cancer as you view it?
- What do I tell my children, husband, parents, and other family members?

In addition to these sample questions, be sure to write down some questions of your own. For instance, you might want specific information about anticipated recovery times so that you can plan your work schedule. Or you may want to ask about second opinions or about clinical trials for which you may qualify.

Other health care professionals, such as nurses and social workers, may have the answers to some of your questions. You can find more information about communicating with your health care team in our document *Talking With Your Doctor*.

What will happen after treatment for vulvar cancer?

For some people with vulvar cancer, treatment may remove or destroy the cancer. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about cancer coming back. (When cancer comes back after treatment, it is called *recurrence*.) This is a very common concern in people who have had cancer.

It may take a while before your fears lessen. But it may help to know that many cancer survivors have learned to live with this uncertainty and are living full lives. Our document *Living With Uncertainty: The Fear of Cancer Recurrence* gives more detailed information on this.

For other people, the cancer may never go away completely. These people may get regular treatments with chemotherapy, radiation therapy, or other therapies to try to help keep the cancer in check. Learning to live with cancer that does not go away can be difficult and very stressful. It has its own type of uncertainty. Our document *When Cancer Doesn't Go Away* talks more about this.

Follow-up care

When treatment ends, your doctors will still want to watch you closely. It is very important to go to all of your follow-up appointments. During these visits, your doctors will ask questions about any problems you may have and may do exams and lab tests or x-rays and scans to look for signs of cancer or treatment side effects. Almost any cancer treatment can have side effects. Some may last for a few weeks to months, but others can last the rest of your life. This is the time for you to talk to your cancer care team about any changes or problems you notice and any questions or concerns you have.

It is important to keep health insurance. Tests and doctor visits cost a lot, and even though no one wants to think of their cancer coming back, this could happen.

Should your cancer come back, our document *When Your Cancer Comes Back: Cancer Recurrence* can give you information on how to manage and cope with this phase of your treatment.

Seeing a new doctor

At some point after your cancer diagnosis and treatment, you may find yourself seeing a new doctor who does not know anything about your medical history. It is important that you be able to give your new doctor the details of your diagnosis and treatment. Gathering these details soon after treatment may be easier than trying to get them at some point in the future. Make sure you have the following information handy:

- A copy of your pathology report(s) from any biopsies or surgeries
- If you had surgery, a copy of your operative report(s)
- If you had radiation, a copy of your radiation treatment summary
- If you were hospitalized, a copy of the discharge summary that doctors prepare when patients are sent home from the hospital
- If you had chemotherapy (or topical therapy), a list of your drugs, drug doses, and when you took them
- Copies of any imaging tests (like CT scans and MRIs) – these can often be placed on a CD or DVD

The doctor may want copies of this information for his records, but always keep copies for yourself.

Can I get another cancer after having vulvar cancer?

Cancer survivors can be affected by a number of health problems, but often their greatest concern is facing cancer again. If a cancer comes back after treatment it is called a "recurrence." But some cancer survivors may develop a new, unrelated cancer later. This is called a "second cancer." No matter what type of cancer you have had, it is still possible to get another (new) cancer, even after surviving the first.

Unfortunately, being treated for cancer doesn't mean you can't get another cancer. People who have had cancer can still get the same types of cancers that other people get. In fact, certain types of cancer and cancer treatments can be linked to a higher risk of certain second cancers.

Survivors of vulvar cancer can get any type of second cancer, but they have an increased risk of:

- A second vulvar cancer (this is different than the first cancer coming back)
- Anal cancer
- Vaginal cancer
- Mouth and throat cancer
- Cancer of the voice box (larynx)
- Lung cancer
- Cancer of the brain and central nervous system

Many of these cancers are linked to smoking and/or infection with human papilloma virus (HPV), which are also risk factors for vulvar cancer.

Follow-up after treatment

After completing treatment for vulvar cancer see their doctors regularly to look for signs of their cancer coming back, as well as a second vulvar cancer, or new cancers of the vagina and anus. Experts do not recommend additional testing to look for second cancers in patients without symptoms. Let your doctor know about any new symptoms or problems, because they could be caused by the cancer coming back or by a new disease or second cancer.

Survivors of vulvar cancer should follow the American Cancer Society guidelines for the early detection of cancer and stay away from tobacco products. Smoking increases the risk of many of the second cancers seen in women treated for vulvar cancer.

To help maintain good health, survivors should also:

- Achieve and maintain a healthy weight
- Adopt a physically active lifestyle
- Consume a healthy diet, with an emphasis on plant foods
- Limit consumption of alcohol to no more than 1 drink per day

These steps may also lower the risk of some cancers.

See *Second Cancers in Adults* for more information about causes of second cancers.

Lifestyle changes after vulvar cancer

You can't change the fact that you have had cancer. What you can change is how you live the rest of your life -- making choices to help you stay healthy and feel as well as you can. This can be a time to look at your life in new ways. Maybe you are thinking about how to improve your health over the long term. Some people even start during cancer treatment.

Making healthier choices

For many people, a diagnosis of cancer helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try to eat better or get more exercise. Maybe you could cut down on the alcohol, or give up tobacco. Even things like keeping your stress level under control may help. Now is a good time to think about making changes that can have positive effects for the rest of your life. You will feel better and you will also be healthier.

You can start by working on those things that worry you most. Get help with those that are harder for you. For instance, if you are thinking about quitting smoking and need help, call the American Cancer Society for information and support. You can also ask for our document *Guide to Quitting Smoking*.

Eating better

Eating right can be hard for anyone, but it can get even tougher during and after cancer treatment. Treatment may change your sense of taste. Nausea can be a problem. You may

not feel like eating and lose weight when you don't want to. Or you may have gained weight that you can't seem to lose. All of these things can be very frustrating.

If treatment caused weight changes or eating or taste problems, do the best you can and keep in mind that these problems usually get better over time. You may find it helps to eat small portions every 2 to 3 hours until you feel better. You may also want to ask your cancer team about seeing a dietitian, an expert in nutrition who can give you ideas on how to deal with these treatment side effects.

One of the best things you can do after cancer treatment is start healthy eating habits. You may be surprised at the long-lasting benefits of some simple changes, like increasing the variety of healthy foods you eat. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol intake may lower your risk for a number of types of cancer, as well as having many other health benefits.

For more information, see our document *Nutrition and Physical Activity During and After Cancer Treatment: Answers to Common Questions*.

Rest, fatigue, and exercise

Extreme tiredness, called *fatigue*, is very common in people treated for cancer. This is not a normal tiredness, but a "bone-weary" exhaustion that doesn't get better with rest. For some people, fatigue lasts a long time after treatment, and can make it hard for them to exercise and do other things they want to do. But exercise can help reduce fatigue. Studies have shown that patients who follow an exercise program tailored to their personal needs feel better physically and emotionally and can cope better, too.

If you were sick and not very active during treatment, it is normal for your fitness, endurance, and muscle strength to decline. Any plan for physical activity should fit your own situation. An older person who has never exercised will not be able to take on the same amount of exercise as a 20-year-old who plays tennis twice a week. If you haven't exercised in a few years, you will have to start slowly – maybe just by taking short walks.

Talk with your health care team before starting anything. Get their opinion about your exercise plans. Then, try to find an exercise buddy so you're not doing it alone. Having family or friends involved when starting a new exercise program can give you that extra boost of support to keep you going when the push just isn't there.

If you are very tired, you will need to balance activity with rest. It is OK to rest when you need to. Sometimes it's really hard for people to allow themselves to rest when they are used to working all day or taking care of a household, but this is not the time to push yourself too hard. Listen to your body and rest when you need to. (For more information on dealing with fatigue, please see *Fatigue in People With Cancer* and *Anemia in People With Cancer*.)

Keep in mind exercise can improve your physical and emotional health.

- It improves your cardiovascular (heart and circulation) fitness.
- Along with a good diet, it will help you get to and stay at a healthy weight.
- It makes your muscles stronger.
- It reduces fatigue and helps you have more energy.
- It can help lower anxiety and depression.
- It can make you feel happier.
- It helps you feel better about yourself.

And long term, we know that getting regular physical activity plays a role in helping to lower the risk of some cancers, as well as having other health benefits.

How does having vulvar cancer affect your emotional health?

When treatment ends, you may find yourself overcome with many different emotions. This happens to a lot of people. You may have been going through so much during treatment that you could only focus on getting through each day. Now it may feel like a lot of other issues are catching up with you.

You may find yourself thinking about death and dying. Or maybe you're more aware of the effect the cancer has on your family, friends, and career. You may take a new look at your relationship with those around you. Unexpected issues may also cause concern. For instance, as you feel better and have fewer doctor visits, you will see your health care team less often and have more time on your hands. These changes can make some people anxious.

Almost everyone who has been through cancer can benefit from getting some type of support. You need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, church or spiritual groups, online support communities, or one-on-one counselors. What's best for you depends on your situation and personality. Some people feel safe in peer-support groups or education groups. Others would rather talk in an informal setting, such as church. Others may feel more at ease talking one-on-one with a trusted friend or counselor. Whatever your source of strength or comfort, make sure you have a place to go with your concerns.

The cancer journey can feel very lonely. It is not necessary or good for you to try to deal with everything on your own. And your friends and family may feel shut out if you do not include them. Let them in, and let in anyone else who you feel may help. If you aren’t sure who can help, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you. You can also read our

document *Distress in People with Cancer* or see the Emotional Side Effects section of our website for more information.

If treatment for vulvar cancer stops working

If cancer keeps growing or comes back after one kind of treatment, it is possible that another treatment plan might still cure the cancer, or at least shrink it enough to help you live longer and feel better. But when a person has tried many different treatments and the cancer has not gotten any better, the cancer tends to become resistant to all treatment. If this happens, it's important to weigh the possible limited benefits of a new treatment against the possible downsides. Everyone has their own way of looking at this.

This is likely to be the hardest part of your battle with cancer -- when you have been through many medical treatments and nothing's working anymore. Your doctor may offer you new options, but at some point you may need to consider that treatment is not likely to improve your health or change your outcome or survival.

If you want to continue to get treatment for as long as you can, you need to think about the odds of treatment having any benefit and how this compares to the possible risks and side effects. In many cases, your doctor can estimate how likely it is the cancer will respond to treatment you are considering. For instance, the doctor may say that more chemo or radiation might have about a 1% chance of working. Some people are still tempted to try this. But it is important to think about and understand your reasons for choosing this plan.

No matter what you decide to do, you need to feel as good as you can. Make sure you are asking for and getting treatment for any symptoms you might have, such as nausea or pain. This type of treatment is called palliative care.

Palliative care helps relieve symptoms, but is not expected to cure the disease. It can be given along with cancer treatment, or can even be cancer treatment. The difference is its purpose - the main purpose of palliative care is to improve the quality of your life, or help you feel as good as you can for as long as you can. Sometimes this means using drugs to help with symptoms like pain or nausea. Sometimes, though, the treatments used to control your symptoms are the same as those used to treat cancer. For instance, radiation might be used to help relieve bone pain caused by cancer that has spread to the bones. Or chemo might be used to help shrink a tumor and keep it from blocking the bowels. But this is not the same as treatment to try to cure the cancer. You can read more about this in our document *Palliative or Supportive Care*.

At some point, you may benefit from hospice care. This is special care that treats the person rather than the disease; it focuses on quality rather than length of life. Most of the time, it is given at home. Your cancer may be causing problems that need to be managed, and hospice focuses on your comfort. You should know that while getting hospice care often means the end of treatments such as chemo and radiation, it doesn't mean you can't

have treatment for the problems caused by your cancer or other health conditions. In hospice the focus of your care is on living life as fully as possible and feeling as well as you can at this difficult time. You can learn more about hospice in our document called *Hospice Care*.

Staying hopeful is important, too. Your hope for a cure may not be as bright, but there is still hope for good times with family and friends -- times that are filled with happiness and meaning. Pausing at this time in your cancer treatment gives you a chance to refocus on the most important things in your life. Now is the time to do some things you've always wanted to do and to stop doing the things you no longer want to do. Though the cancer may be beyond your control, there are still choices you can make.

You can learn more about the changes that occur when treatment stops working, and about planning ahead for yourself and your family, in our documents *Advance Directives* and *Nearing the End of Life*.

What's new in vulvar cancer research and treatment?

Research is being done to find new ways to prevent and treat cancer of the vulva. There are some promising new developments.

Oncogenes and tumor suppressor genes

Scientists are learning more about how certain genes called *oncogenes* and *tumor suppressor genes* control cell growth and how changes in these genes cause normal vulvar cells to become cancerous. This information is already being used to develop new drugs that counteract the effects of these gene changes. The ultimate goal of this research is gene therapy. Gene therapy involves replacing the damaged genes in cancer cells with normal genes in order to stop the abnormal behavior of these cells.

HPV vaccines

Vaccines for preventing and treating vulvar and cervical cancer are being developed and tested.

Some of these vaccines are meant to prevent infection with certain types of HPV by boosting the body’s immunity to them. Two HPV vaccines, Gardasil and Cervarix, are available. Both vaccines are able to prevent infection with HPV types 16 and 18 and prevent pre-cancerous changes in the cervix. Studies have shown that Gardasil can also prevent anal, vulvar, and vaginal cancers caused by HPV types 6 and 11. Other preventive vaccines are also under study.

Some vaccines being studied are intended to help the immune systems of women with HPV infections destroy the virus and cure the infection before a cancer develops.

Other vaccines are meant to help women who already have a cancer or pre-cancer. These vaccines attempt to produce an immune reaction to the parts of the virus (E6 and E7 proteins) that specifically contribute to the abnormal growth of cancer cells. It is hoped that this immunity will kill the cancer cells or stop them from growing. A vaccine of this type was tested in women with grade 3 vulvar intraepithelial neoplasia (VIN3) that tested positive for HPV-16. Most women treated had their VIN lesions shrink, and in some the lesions even went away completely.

Drug treatment

There have been case reports of using drugs known as *targeted therapies* to treat vulvar cancers. These drugs do not have the same kind of side effects as traditional chemo drugs do. So far, the drugs cetuximab and erlotinib have been tried and doctors have reported some success in a few patients. Sometimes cetuximab is combined with cisplatin chemotherapy for treatment. Further studies of these drugs are needed.

Combining surgery, radiation therapy, and chemotherapy

Clinical trials are underway to determine the best way to combine surgery, radiation therapy, and chemotherapy. For example, these trials will provide information about whether certain groups of patients benefit from radiation after surgery and whether patients with cancer that has spread to lymph nodes benefit from chemotherapy or pelvic radiation therapy.

Additional resources for vulvar cancer

More information from your American Cancer Society

Here is more information you might find helpful. You can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, www.cancer.org.

Living with Cancer

After Diagnosis: A Guide for Patients and Families (also available in Spanish)

Living With Uncertainty: The Fear of Cancer Recurrence

Distress in People With Cancer

Sexuality for the Woman With Cancer (also available in Spanish)

When Cancer Doesn’t Go Away

When Your Cancer Comes Back: Cancer Recurrence

Cancer treatments and side effects

A Guide to Chemotherapy (also available in Spanish)

Understanding Radiation Therapy: A Guide for Patients and Families (also available in Spanish)

A Guide to Cancer Surgery (also available in Spanish)

Understanding Lymphedema (For Cancers Other Than Breast Cancer)

More cancer information

HPV and HPV Testing

HPV Vaccines

Melanoma Skin Cancer

Family and caregiver concerns

Talking With Friends and Relatives About Your Cancer (also in Spanish)

What It Takes to Be a Caregiver

Caring for the Patient With Cancer at Home: A Guide for Patients and Families (also available in Spanish)

Helping Children When a Family Member Has Cancer: Dealing With Diagnosis (also available in Spanish)

Work, insurance, and finances

Health Insurance and Financial Assistance for the Cancer Patient

Returning to Work After Cancer Treatment

Working During Cancer Treatment

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at cancer.org/bookstore to find out about costs or to place an order.

National organizations and websites*

In addition to the American Cancer Society, other sources of patient information and support include*:

Foundation for Women's Cancer (formerly Gynecologic Cancer Foundation)
Toll-free number: 1-800-444-4441
Website: www.foundationforwomenscancer.org

> Offers referrals to gynecologic oncologists and has information about how to prevent, detect, and treat female cancer; also the booklet, "Renewing Intimacy and Sexuality After Gynecologic Cancer." Educational programs for survivors are also offered throughout the country.

National Cancer Institute
Toll-free number: 1-800-4-CANCER (1-800-422-6237)
Website: www.cancer.gov

> Offers current information about many types of cancer, diagnosis, treatment, and research, as well as information for the family and children of people with cancer

National Coalition for Cancer Survivorship (NCCS)
Toll-free number: 1-888- 650-9127
1-877-622-7937(1-877-NCCS-YES) for some publications and Cancer Survivor Toolbox® orders
Website: www.canceradvocacy.org

> Has publications on many cancer-related topics; also offers the Cancer Survival Toolbox – a free program that teaches skills that can help people meet the challenges of cancer

**Inclusion on this list does not imply endorsement by the American Cancer Society*

No matter who you are, we can help. Contact us anytime day or night, for information and support. Call us at **1-800-227-2345** or visit our website at www.cancer.org

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Last Medical Review: 7/2/2014
Last Revised: 3/18/2015

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