About This Booklet

This booklet was developed in support of the Centers for Disease Control and Prevention’s (CDC) *Inside Knowledge: Get the Facts About Gynecologic Cancer* campaign. The campaign helps women get the facts about gynecologic cancer by providing important “inside knowledge” about their bodies and health.

As you read this booklet, you will learn about the different types of gynecologic cancer. These are cancers that affect the female reproductive organs. They include cervical, ovarian, uterine, vaginal, and vulvar cancers. You will find information on:

- Signs, symptoms, and risk factors related to each gynecologic cancer.
- What you can do to help prevent gynecologic cancer.
- What to do if you have symptoms.
- What to do if you think you may be at increased risk for developing a gynecologic cancer.
- Questions to ask your doctor.

Each year, approximately 71,500 women in the United States are diagnosed with a gynecologic cancer. While all women are at risk for developing gynecologic cancers, few will ever develop one. Still, it is important to know the signs because there is no way to know for sure who will get a gynecologic cancer. The information included in this booklet will help you recognize any warning signs, so you can ask your health care provider about them. These signs and symptoms often are related to something other than gynecologic cancer. But it is important for your overall health to know what is causing them.

Important words to know appear in *italics* and are included with definitions in the glossary at the back of the booklet.
The Inside Knowledge: Get the Facts About Gynecologic Cancer campaign is an initiative that supports the Gynecologic Cancer Education and Awareness Act of 2005, or Johanna’s Law, which was unanimously passed by the 109th Congress in 2006, and signed into law in January 2007.

To find out more:
Visit www.cdc.gov/cancer/knowledge
Call 1-800-CDC-INFO
Gynecologic Cancer Overview

What is cancer?

Cancer is a group of diseases in which abnormal cells in the body divide and grow out of control. These abnormal cells can spread to other parts of the body. When this happens, it is called metastasis. There are more than 100 different types of cancer. Cancer is usually named for the organ or part of the body where it starts, or the type of cell in which it starts, even if it spreads to other body parts later. For example, cancer that begins in the ovaries and spreads to another organ is still called ovarian cancer, even after it has spread. Treatment can be most effective when cancer is found at an early stage.
What causes cancer?
In most cases, the exact cause of cancer is not known. However, it is clear that certain changes in cells can cause cancer. These cell changes can be acquired or inherited. If the changes are acquired, they are caused by environmental factors and things people do, such as smoking. Almost all cervical cancers and some vaginal and vulvar cancers are caused by human papillomavirus, also called HPV, which is an acquired virus. However, if the changes are inherited, they are passed from parent to child through genes.

What is gynecologic cancer?
Gynecologic cancer is any cancer that starts in a woman’s reproductive organs.

While they are often discussed as a group, each gynecologic cancer is unique. Each has different signs, symptoms, and risk factors (things that may increase your chance of getting each cancer). For some of these cancers, there are ways to lower your risk.

The five main types of gynecologic cancer are:

- **Cervical cancer**: Begins in the cervix, the lower part of the uterus (or womb).
- **Ovarian cancer**: Begins in the ovaries, located on each side of the uterus.
- **Uterine cancer**: Begins in the uterus, the pear-shaped organ in a woman’s pelvis where the baby grows when a woman is pregnant.
- **Vaginal cancer**: Begins in the vagina, the hollow, tube-like channel between the bottom of the uterus and the outside of the body. It is also called the birth canal.
- **Vulvar cancer**: Begins in the vulva, the outer part of the female genital organs, which includes the inner and outer lips of the vagina, the clitoris, and the opening of the vagina and its glands.

Additional types of gynecologic cancer exist, and include fallopian tube cancer and primary peritoneal cancer. (Please see p. 13 for more information)

Who gets gynecologic cancer?
While all women are at risk for gynecologic cancer, this risk generally increases with age.

Each year in the United States, approximately 71,500 women are diagnosed with gynecologic cancer and approximately 26,500 women die from it.
What increases a woman’s risk of getting gynecologic cancer?

There is no way to know which women will get gynecologic cancer. Each specific type of gynecologic cancer has a unique set of risk factors. These are discussed in detail for each cancer on the pages that follow.

Human papillomavirus (HPV) infections that do not go away increase the risk of getting several types of gynecologic cancers. HPV is a common sexually transmitted virus that can cause cervical, vaginal, and vulvar cancers. It is one of the most well-established risk factors for these three cancers.

For more information about your risk, talk to your doctor, nurse, or other health care professional*.

* Please note that throughout the brochure the word “doctor” will be used to refer to doctors, nurses, and other health care professionals.

Who gets HPV?

HPV is a common virus with more than 100 different kinds or types. More than 30 of the types can be passed from one person to another during sex. HPV can occur in both men and women. At least half of all sexually active people will get HPV at some point in their lives.

Any woman who has ever had sex is at risk for getting HPV. Women are more likely to have HPV if they started having sex at an early age and if they or their partner have had sex with several others.

Condoms can lower your chance of getting HPV, if they are used all the time and the right way. However, HPV can infect areas that are not covered by a condom, so condoms do not fully protect against HPV.

How does HPV cause cancer?

Most of the time, people who become infected with HPV will not have any symptoms and the infection will clear up on its own. However, when the infection does not clear up, it can cause normal cells to turn abnormal. Over time, these abnormal cells can turn into cancer of the cervix, vagina, or vulva.

How likely am I to get a gynecologic cancer if I have HPV?

Many people will have an HPV infection at some time in their lives, but few women will get cervical, vaginal, or vulvar cancer—the gynecologic cancers that are linked to HPV.
How can I help prevent gynecologic cancer or find it early?
While there is no known way to prevent all types of gynecologic cancer, there are things you can do that may help lower your chance of getting them or help to find them early. It is important to find gynecologic cancers early, when treatment can be most effective.

Pay attention to your body and know what is normal for you. If you have any abnormal vaginal bleeding, or if you have any other signs and symptoms of gynecologic cancer for two weeks or longer and they are not normal for you, talk to a doctor right away. The symptoms may be caused by something other than cancer, but the only way to know is to see a doctor.

Make healthy lifestyle choices. For overall good health, eat a diet rich in fruits and vegetables; exercise regularly; maintain a healthy weight; avoid smoking; and practice safe sex.

Know your family health history and share it with your doctor.

Get the HPV vaccine if you are at an age when it is recommended. It protects against the types of HPV that most often cause cervical, vaginal, and vulvar cancers. It is given in a series of three shots. The vaccine is recommended for 11- and 12-year-old girls. (Note: The vaccine can be given to girls beginning at age 9.) It also is recommended for girls and women aged 13 through 26 years who did not get any or all of the shots when they were younger.

Get regular Pap tests. Pap tests (or Pap smears) are one of the most reliable and effective cancer screening tests available. Pap tests can find precancerous changes on the cervix that can be treated so that cervical cancer is prevented. A Pap test can also find cervical cancer early, when treatment is most effective. The only cancer the Pap test screens for is cervical cancer.

Talk to a doctor about whether the HPV test is right for you.

Pap test. The Pap test can find precancerous changes on the cervix that can be treated to prevent cervical cancer. A Pap test also can find cervical cancer early, when treatment is most effective.

The Pap test does NOT screen for ovarian, uterine, vaginal, or vulvar cancers. Even if you have a Pap test regularly, see your doctor if you notice any signs or symptoms that are not normal for you.

HPV test. The HPV test looks for HPV infection. This test may be used with the Pap test to screen for cervical cancer in women aged 30 years and older. It also is used to provide more information when a Pap test has unclear results.

If you have HPV, follow your doctor’s advice for further testing.
What are the signs and symptoms of gynecologic cancer?

The signs and symptoms shown here are often related to gynecologic cancer. However, not all women with gynecologic cancer have the same symptoms. And sometimes symptoms are difficult to recognize because they may be caused by or related to other conditions. That is why it is important to pay attention to your body and know what is normal for you.

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<th>Symptoms</th>
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Questions to Ask Your Doctor

When visiting a doctor, it may be helpful to bring a list of questions to ask and to take notes during your visit. Consider asking the following questions:

1) What is my risk for getting a gynecologic cancer, such as cervical, ovarian, uterine, vaginal, or vulvar cancer?

2) When should I have my next Pap test?

3) What do my Pap test results mean?

4) Is the HPV test right for me?

5) When can I stop getting a Pap test?

6) Are there any other gynecologic cancer tests that I need, based on my personal health and family cancer history? If so, what are they? Why do I need them? How do they work?

7) I have noticed [insert any symptoms you are experiencing], which is not normal for me. Could this be caused by a gynecologic cancer? If so, what should I do next?

Talk to a doctor right away if:

- You have any abnormal vaginal bleeding between periods, after sex, or after menopause.

- You have any of the other signs and symptoms of gynecologic cancer for two weeks or longer and they are not normal for you.

The symptoms may be caused by something other than cancer, but the only way to know is to see a doctor.
Cervical Cancer

What is cervical cancer?
When cancer starts in the cervix, it is called cervical cancer. The cervix is the lower, narrow end of the uterus (or womb). The cervix connects the upper part of the uterus to the vagina (the birth canal).

Cervical cancer is the only gynecologic cancer that can be prevented, by having screening tests routinely and following up, as necessary. It also is highly curable when found and treated early.
Who gets cervical cancer?
All women who have a cervix are at risk for cervical cancer. Women who have had a total hysterectomy, which includes the removal of the cervix, are not at risk for cervical cancer. (If you are not sure if your cervix was removed during a hysterectomy, ask your doctor.)

Cervical cancer occurs most often in women over the age of 30. Each year, approximately 12,000 women in the United States get cervical cancer.

Cervical cancer is among the leading causes of death worldwide, and used to be the leading cause of cancer death for women in the United States. However, in the past 40 years, there has been a major decrease in the number of deaths from cervical cancer. This decline largely is due to many women getting regular Pap tests, which can find precancerous changes that can be treated before they turn into cancer.

What are the symptoms of cervical cancer?
Early on, cervical cancer may not cause signs and symptoms. In later stages, cervical cancer may cause bleeding—especially after sex—or discharge from the vagina that is not normal for you.

If you have unusual bleeding or discharge, see a doctor. The symptoms may be caused by something other than cervical cancer, but the only way to know is to see a doctor.

What raises a woman’s chance of getting cervical cancer?
Certain types of human papillomavirus (HPV) may lead to cervical cancer. Almost all cervical cancers are linked to HPV. (See Gynecologic Cancer Overview for more information about HPV.) However, there are other things that can increase your risk, including:

- Smoking.
- Having HIV or another condition that makes it hard for your body to fight off health problems.
- Using birth control pills for a long time.
- Having given birth to three or more children.
- Exposure before birth (while in the womb) to Diethylstilbestrol (DES), which is a man-made form of estrogen prescribed until 1971 to help women with pregnancy complications.

How can I help lower my chance of getting cervical cancer?
There are several things you can do that may reduce your chance of getting cervical cancer.

1) Protect yourself from HPV.
- Talk to your doctor about getting the HPV vaccine, which protects against the types of HPV that most often cause cervical, vaginal, and vulvar cancers.
- Use condoms during sex.
- Limit your number of sexual partners.

2) See a doctor regularly for a Pap test that looks for cervical precancers and cancer. Be sure to follow up with the doctor if your test results are not normal.

3) Don’t smoke. Smoking harms all of your body’s cells, including your cervical cells. If you smoke and have HPV, you have a higher chance of getting cervical cancer. If you smoke, ask a doctor for help quitting.
Are there ways to prevent cervical cancer or find it early?
Yes. The Pap test, HPV test, and HPV vaccine all help to prevent cervical cancer. The Pap test and HPV test also help to find it early.

1) The Pap test is one of the most reliable and effective screening tests available. Getting a Pap test regularly is important because it can find precancerous changes on the cervix that can be simply and effectively treated to prevent cervical cancer. A Pap test also can find cervical cancer early, when treatment is most effective.

The only cancer the Pap test screens for is cervical cancer. It does not screen for any other type of cancer.

Most cervical cancers occur among women who have never had a Pap test or have not had one in the last five years.

2) The HPV test looks for HPV—the virus that can cause cell changes on the cervix. This test often is used to screen for cervical cancer, along with the Pap test, in women aged 30 years and older. It also is used to provide more information when a Pap test has unclear results.

3) Two HPV vaccines are available to protect females against the types of HPV that cause most cervical cancers, and vaginal and vulvar cancers. Both vaccines are recommended for 11- and 12-year-old girls, and for females 13 through 26 years of age who did not get any or all of the shots when they were younger. These vaccines also can be given to girls as young as 9 years of age. It is recommended that females get the same vaccine brand for all three doses, whenever possible. It is important to note that even women who are vaccinated against HPV need to have regular Pap tests to screen for cervical cancer.

When and how often should I get a Pap test?
All women should start getting regular Pap tests at age 21, or within three years of the first time they have sex—whichever comes first.

How often you get a Pap test depends on many factors. If your screening tests have been normal, your doctor may tell you that you do not need another screening test for up to three years. But you should still go to the doctor regularly for check-ups that may include a pelvic exam.

It is important for you to continue getting a Pap test as directed by your doctor—even if you think you are too old to have a child or are not having sex anymore. If you are older than 65 and have had normal Pap test results for several years, or if you have had your cervix removed as part of a total hysterectomy for non-cancerous conditions, like fibroids, your doctor may tell you it is okay to stop getting regular Pap tests.

What does my Pap test result mean?
Your Pap test result will come back as “normal,” “unclear,” or “abnormal.”

Normal: A normal (or “negative”) result means that no cell changes were found on your cervix. However, it is still important to get Pap tests regularly because new cell changes can develop.

Unclear: The doctor may use other words to describe this result, including equivocal, inconclusive, or ASC-US. These all mean the same thing: that your cervical cells look like they could be abnormal. It is not clear if this is related to HPV or to other life changes, like pregnancy, menopause, or some other infection. The HPV test can help find out if your cell changes are related to HPV.
Abnormal: An abnormal result means that cell changes were found on your cervix. But don’t be alarmed—this does not necessarily mean you have cervical cancer. Most of the time, minor changes go back to normal on their own. But more serious changes—precancers—can turn into cancer if they are not treated. If your test is abnormal, it is very important to follow up with your doctor because you likely will need more tests or treatment.

Where can I find free or low-cost cervical cancer screening tests? You may be able to get free or low-cost cervical cancer screening tests if you:

- **Have health insurance.** Contact your insurance provider to find out if cervical cancer screening is covered.
- **Are eligible for Medicaid.** To learn more, call 1-800-MEDICARE or visit www.cms.hhs.gov/home/medicaid.asp.
- **Are aged 65 years or older.** Medicare pays for the Pap test every two years, or every year for some women. To learn more, call 1-800-MEDICARE or visit www.cms.hhs.gov/home/medicare.asp.
- **Have a low income or do not have health insurance.** CDC’s National Breast and Cervical Cancer Early Detection Program offers free or low-cost screening. To learn more, call 1-800-CDC-INFO or visit www.cdc.gov/cancer/nbccedp.

Where can I find free or low-cost HPV vaccines? Girls through 18 years of age may be able to get the HPV vaccine for free or at low-cost. To learn more, call 1-800-CDC-INFO or visit www.cdc.gov/vaccines/programs/vfc/parents/.
Ovarian Cancer

What is ovarian cancer?
When cancer starts in the ovaries, it is called ovarian cancer. Women have two ovaries that are located in the pelvis, one on each side of the uterus. The ovaries make female hormones and produce eggs.

Who gets ovarian cancer?
All women are at risk for ovarian cancer, but older women are more likely to get the disease than younger women. About 90 percent of women who get ovarian cancer are older than 40. The greatest number of ovarian cancers occurs in women aged 60 years or older. Women who have had both ovaries removed have a much lower risk of ovarian cancer.

Each year, approximately 20,000 women in the United States get ovarian cancer.
What are the signs and symptoms of ovarian cancer?
Ovarian cancer may cause the following signs and symptoms:

- Vaginal bleeding, such as irregular periods, bleeding that is heavier than normal for you, or that occurs when you are past menopause.

- Discharge from your vagina that is not normal for you.

- Pain or pressure in the pelvic or abdominal area.

- Back pain.

- Bloating or feeling full quickly while eating.

- Change in bathroom habits, such as having to pass urine very often and with greater than usual urgency, constipation, or diarrhea.

Pay attention to your body and know what is normal for you. If you have unusual vaginal bleeding, see a doctor right away. If you have any of the other signs for two weeks or longer and they are not normal for you, see a doctor. They may be caused by something other than cancer, but the only way to know is to see a doctor.

What raises a woman's chance of getting ovarian cancer?
There is no way to know if you will get ovarian cancer. However, there are several factors that may increase the chance that you will get it, including if you:

- Are middle-aged or older.

- Have close family members (such as your mother, sister, aunt, or grandmother) on either your mother’s or your father’s side, who have had ovarian cancer.

- Have had breast, uterine, or colorectal cancer.

- Have an Eastern European (Ashkenazi) Jewish background.

- Have never given birth or have had trouble getting pregnant.

- Have endometriosis.

- Have tested positive for a genetic abnormality called a BRCA1 or BRCA2.

In addition, some studies suggest that women who take estrogen by itself (estrogen without progesterone) for 10 or more years may have an increased risk of ovarian cancer.

If one or more of these is true for you, it does not mean you will get ovarian cancer. But you should talk to a doctor about your risk.
How can I help prevent or lower my chance of getting ovarian cancer?

There is no known way to prevent ovarian cancer. But these things are associated with a lower chance of getting it:

- Having used birth control pills for more than five years.
- Having had a tubal ligation (getting your tubes tied), both ovaries removed, or a hysterectomy.
- Having given birth.

Are there ways to find ovarian cancer early?

Currently there is no effective screening test for ovarian cancer, and it can be very hard to identify ovarian cancer early. The signs and symptoms of ovarian cancer are not always clear and may be hard to recognize. The *Pap test* does not screen for ovarian cancer. The only cancer the *Pap test screens for is cervical cancer.* That is why it is so important to pay attention to your body and know what is normal for you. If you notice any changes in your body that last for two weeks or longer and may be a sign or symptom of ovarian cancer, talk to a doctor and ask about possible causes.
Rectovaginal pelvic exams, transvaginal ultrasounds, and CA-125 blood tests can be used in combination to help diagnose ovarian cancer. Ask a doctor about these tests, if:

- You have any unexplained signs or symptoms of ovarian cancer that last for two or more weeks.
- You had breast, uterine, or colorectal cancer.
- A close relative had ovarian cancer or you tested positive for the BRCA1 or BRCA2 gene.

When ovarian cancer is found early, treatment can be most effective.

Should I have a genetic test for ovarian cancer?
If you or your family have a history of breast or ovarian cancer, your doctor may recommend genetic testing and counseling. Genetic testing is useful for a very small percentage of women who have a family history of cancer. It is not recommended for all women, but it is important for all women to know their family history.

Genetic testing can help some women find out if they have an increased chance of developing breast and ovarian cancer. It works by finding changes or alterations in genes known as breast cancer susceptibility genes 1 and 2 (BRCA1 and BRCA2).

If you are considering genetic testing, you should get genetic counseling to help you decide whether to get tested, and to learn what the test results may mean for you.

If the following is true for you, you may benefit from genetic counseling and testing:

You have an Eastern European (Ashkenazi) Jewish background, and on your mother’s or father’s side you have one of the following:

- A first-degree relative (parent, sibling, or child) with breast or ovarian cancer.
- Two second-degree relatives (grandparent, grandchild, uncle, aunt, nephew, niece, or half-sibling) on the same side of the family with breast or ovarian cancer.

You do not have an Eastern European (Ashkenazi) Jewish background, but on your mother’s or father’s side you have one of the following:

- Two first-degree relatives (i.e., parent, sibling, or child) with breast cancer and at least one of them was diagnosed at or before the age of 50.
- A combination of three or more first- or second-degree relatives with breast cancer, regardless of the age they were when the cancer was diagnosed.
- A combination of breast and ovarian cancer among first- and second-degree relatives.
- A first-degree relative with breast cancer in both breasts.
- A combination of two or more first- or second-degree relatives with ovarian cancer, regardless of the age they were when the cancer was diagnosed.
- A first- or second-degree relative with both breast and ovarian cancer, diagnosed at any age.
- A history of breast cancer in a male relative.
Uterine Cancer

What is uterine cancer?
When cancer starts in the uterus, it is called uterine cancer. The uterus is the pear-shaped organ in a woman’s pelvis. Also called the womb, the uterus is where the baby grows when a woman is pregnant.

Who gets uterine cancer?
All women—except those whose uterus was removed by having a hysterectomy—are at risk for uterine cancer, and the risk increases with age. Most uterine cancers are found in women who are going through or have gone through menopause. Each year, approximately 35,000 women in the United States get uterine cancer.

What are the signs and symptoms of uterine cancer?
Signs and symptoms of uterine cancer include:

• Vaginal discharge or bleeding that is not normal for you. The bleeding may be abnormal because of how heavy it is or when it happens, such as bleeding after you have gone through menopause; bleeding between periods; or any other bleeding that is longer or heavier than is normal for you.

• Pain or pressure in your pelvis.

If you have bleeding that is not normal for you, especially bleeding after menopause, see a doctor right away. If you have pain or pressure in your pelvis or abnormal vaginal discharge for two weeks or longer, see a doctor. These things may be caused by something other than cancer, but the only way to know is to see a doctor.

There are two main types of uterine cancer:

Endometrial cancer: The most common type of uterine cancer. Endometrial cancer forms in the lining of the uterus, which is called the endometrium.

Uterine sarcoma: A rare type of uterine cancer that forms in the muscle or other tissue of the uterus.

When uterine cancer is found early, treatment is most effective.
What raises a woman’s chance of getting uterine cancer?
There is no way to know who will get uterine cancer. However, several factors may increase the chance that you will get uterine cancer, including if you:

- Are older than age 50.
- Are obese (having an abnormally high, unhealthy amount of body fat).
- Take estrogen by itself for hormone replacement during menopause. In general, when estrogen is used, it should be in combination with the other female hormone, progesterone.
- Have had trouble getting pregnant, or have had fewer than five periods in a year at any time in your life before starting menopause.
- Take tamoxifen, a drug used to prevent or treat certain types of breast cancer.

If one or more of these is true for you, it does not mean you will get uterine cancer, but you should talk with a doctor to see if he or she recommends more frequent exams.

Women who have an inherited form of colorectal cancer, called hereditary nonpolyposis colorectal cancer syndrome, have an increased risk of getting uterine cancer. This may be true for you if you have close female relatives (i.e., your mother, grandmother, sister, aunt, or daughter) who have had uterine or ovarian cancer. If so, talk to a doctor about having annual exams and endometrial biopsies, starting at age 35.

How can I help prevent or lower my chance of getting uterine cancer?
There is no known way to prevent uterine cancer. But these things may reduce your chance of getting uterine cancer:

- Using birth control pills.
- Maintaining a healthy weight and being physically active.
- Taking progesterone, if you are taking estrogen.
- Talking with a doctor about how often you should be checked for uterine cancer, especially if you think that you have factors that increase your chance of getting it.

Are there ways to find uterine cancer early?
There are no simple and reliable ways to test for uterine cancer in women who do not have any signs or symptoms. The Pap test does not screen for uterine cancer. The only cancer the Pap test screens for is cervical cancer. This is why it is important to know the signs and symptoms of uterine cancer and to see a doctor if you have any of them.

If you have symptoms or are at a higher risk for uterine cancer, your doctor may perform an endometrial biopsy or a transvaginal ultrasound. These tests can be used to help diagnose or rule out uterine cancer. Your doctor may do this test in his or her office, or may refer you to another doctor. The doctor might perform more tests if the endometrial biopsy does not provide enough information, or if symptoms continue.
Vaginal Cancer

What is vaginal cancer?
When cancer starts in the vagina, it is called vaginal cancer. The vagina, also called the birth canal, is the hollow, tube-like channel between the bottom of the uterus and the outside of the body.

When vaginal cancer is found early, treatment is most effective.

Who gets vaginal cancer?
While vaginal cancer is very rare, all women are at risk. Each year, approximately 1,000 women in the United States get vaginal cancer.

What are the signs and symptoms of vaginal cancer?
Most vaginal cancers do not cause signs or symptoms early on. But if symptoms are present, they may include:

- Vaginal discharge or bleeding that is not normal for you. The bleeding may be abnormal because of how heavy it is, or when it happens, such as bleeding after you have gone through menopause; bleeding between periods; or any other bleeding that is longer or heavier than is normal for you.

- Change in bathroom habits, including having blood in the stool or urine; going to the bathroom more often than usual; or feeling constipated.

- Pain in your pelvis or abdomen, especially when you pass urine or have sex.

If you have abnormal vaginal bleeding, see a doctor right away. If you have any of the other signs for two weeks or longer, see a doctor. They may be caused by something other than cancer, but the only way to know is to see a doctor.

What raises a woman’s chance of getting vaginal cancer?
There is no way to know for sure who will get vaginal cancer. However, these things may increase the chance you will get it:

- Having HPV.

- Having a history of abnormal Pap test results showing abnormal cervical cells or having had cervical cancer.

- Having HIV or another condition that makes it hard for your body to fight off health problems.
• Exposure before birth (while in the womb) to Diethylstilbestrol (DES), which is a man-made form of estrogen that was prescribed until 1971 to help women with pregnancy complications.

• Smoking.

If one or more of these is true for you, it does not mean you will get vaginal cancer. But you should talk to a doctor about whether you need more frequent exams.

How can I help prevent or lower my chance of getting vaginal cancer?
You can lower your chance of developing vaginal cancer by:

• Getting the HPV vaccine, if you are in the age group for which it is recommended. The vaccine protects against the types of HPV that most often cause cervical, vaginal, and vulvar cancers.

• Limiting your number of sexual partners to reduce the risk of getting HPV or HIV.

• Not smoking. Smoking harms all of your body’s cells, including your vaginal cells. If you smoke and have HPV, you have a higher chance of getting vaginal cancer. If you smoke, ask a doctor for help quitting.

Are there ways to find vaginal cancer early?
The best ways to find vaginal cancer early are to get regular checkups and to see a doctor if you have any signs or symptoms. The Pap test does not screen for vaginal cancer. The only cancer the Pap test screens for is cervical cancer. A doctor may perform a pelvic exam to look for signs of vaginal cancer, such as lumps or changes in the vagina, or perform a biopsy to help diagnose vaginal cancer. If you have had abnormal cervical cells or cervical cancer, you may be at a higher risk of getting other HPV-associated cancers, like vaginal cancer. Your doctor may recommend more follow-up tests or visits to check for vaginal cancer.
Vulvar Cancer

What is vulvar cancer?
When cancer starts in the vulva, it is called vulvar cancer. The vulva is the outer part of the female genital organs. It has two folds of skin called the labia. Vulvar cancer most often occurs on the inner edges of the labia.

When vulvar cancer is found early, treatment is most effective.

Who gets vulvar cancer?
While vulvar cancer is very rare, all women are at risk. Each year, approximately 3,500 women in the United States get vulvar cancer.
What are the signs and symptoms of vulvar cancer?
Signs and symptoms of vulvar cancer include:

- Itching, burning, or bleeding on the vulva that does not go away.
- Color changes on the skin of the vulva, where it is redder or whiter than normal for you.
- Skin changes on the vulva, including what looks like a rash or warts.
- Sores, new lumps, or ulcers on the vulva that do not go away.
- Pain in your pelvis, especially when you urinate or have sex.

If you have any of these signs for two weeks or longer and they are not normal for you, see a doctor. They may be caused by something other than cancer, but the only way to know is to see a doctor.

What raises a woman’s chance of getting vulvar cancer?
There is no way to know who will get vulvar cancer. However, the following factors may increase the chance you will get it:

- Having HPV.
- Having a history of abnormal Pap test results showing abnormal cervical cells or having had cervical cancer.
- Having HIV or another condition that makes it hard for your body to fight off health problems.
- Being aged 50 years or older.
- Having chronic vulvar itching or burning.
- Smoking.

If one or more of these is true for you, it does not mean you will get vulvar cancer, but talk to a doctor about whether you need more frequent exams.

How can I help prevent or lower my chance of getting vulvar cancer?
You can lower your chance of developing vulvar cancer by:

- Getting the HPV vaccine, if you are in the age group for which it is recommended. The vaccine protects against the types of HPV that most often cause cervical, vaginal, and vulvar cancers.
- Limiting your number of sexual partners to reduce the risk of getting HPV.
- Not smoking. Smoking harms all of your body’s cells, including your vulvar cells. If you smoke and have HPV, you have a higher chance of getting vulvar cancer. If you smoke, ask a doctor for help quitting.

Are there ways to find vulvar cancer early?
The best ways to find vulvar cancer early are to get regular checkups and to see a doctor if you have signs or symptoms of vulvar cancer for two weeks or longer. The Pap test does not screen for vulvar cancer. The only cancer the Pap test screens for is cervical cancer. A doctor may perform a physical examination to look for skin changes or perform a biopsy to help diagnose vulvar cancer. If you have had abnormal cervical cells or cervical cancer, you may be at a higher risk of getting other HPV-associated cancers, like vulvar cancer. Your doctor may recommend more follow-up tests or visits to check for vulvar cancer.
Gynecologic Cancer Diagnosis
What should I do if my doctor says I have a gynecologic cancer?

If your doctor says you have a gynecologic cancer, you may feel scared, depressed, shocked, worried, angry, confused, and many other emotions. Everyone reacts differently to a cancer diagnosis. There is no one ‘right’ way to react.

As you come to terms emotionally with the diagnosis, here are some practical things you can do as you, your loved ones, and doctor decide on the best medical course of action:

Ask to be referred to a gynecologic oncologist, a doctor who is trained to treat gynecologic cancers. (See p. 24 for information on locating gynecologic oncologists.) Gynecologic oncologists are not located in all geographic areas. If that is the case in your area, you may be referred to other types of doctors who help treat gynecologic cancer, such as gynecologists, medical oncologists, and radiation oncologists. You may have a team of doctors and nurses working with you to create a treatment plan.

When you see a doctor next, you may want to:

• Develop and bring a list of questions to ask.

• Take notes or use an audio recorder during your visit.

• Bring a family member or friend to help listen to and understand what the doctor says.

Before starting treatment, many experts recommend that you get a second opinion about your diagnosis and treatment plan.

What are the types of cancer treatment?

Different types and combinations of cancer treatment are possible, depending on the type of cancer and the stage at which it is diagnosed. Possible treatments include:

• **Surgery:** A surgeon removes as much of the cancer as possible. The extent or possibility of surgery depends on the type of cancer, the stage, and the patient’s overall health.

• **Chemotherapy:** A doctor uses drugs to stop or slow the growth of cancer cells. These drugs also can harm healthy cells, which may cause side effects. Side effects usually get better or go away when chemotherapy is over.

• **Radiation Therapy:** A doctor uses high doses of radiation—high-energy rays—to kill cancer cells and stop them from spreading. Radiation therapy does not hurt while it is being given, but it can cause side effects.

You may want to talk to your doctor about taking part in a clinical trial. Clinical trials are research studies that help determine how well new medical approaches work. (See p. 24 for resources that provide more information about clinical trials.)

What is staging and why do I need it?

Cancer staging describes the size and extent of the disease in the body and whether it has spread from its original site to other parts of the body.

To find out the stage of a gynecologic cancer, your doctor may perform several tests. These results:

• Will help the doctor develop the best possible treatment plan.

• Can be used to estimate the likely outcome or course of the disease.
Resources

For information about gynecologic cancer, visit:
Centers for Disease Control and Prevention
1-800-CDC-INFO
www.cdc.gov/cancer/knowledge

For information about treatment and clinical trials for gynecologic and other cancers, visit:
National Cancer Institute
1-800-4-CANCER
www.cancer.gov

For information about free or low-cost cervical and breast cancer screening, visit:
CDC’s National Breast and Cervical Cancer Early Detection Program
1-800-CDC-INFO
www.cdc.gov/cancer/nbccedp

For help locating a gynecologic oncologist, visit:
Women’s Cancer Network of the Gynecologic Cancer Foundation
www.wcn.org

For more information about Johanna’s Law, visit:
www.johannaslaw.org
**Glossary**

**Abdomen (AB-doh-min):** The area of the body between the chest and pelvis containing the stomach, intestines, liver, and other organs.

**Biopsy (BUY-op-SEE):** A test where a doctor removes a small piece of tissue that is then examined under a microscope to look for abnormal cells that may be cancerous.

**Bloating (BLOHT-ing):** When the area below your stomach swells or feels full.

**BRCA1 and BRCA2:** Both are human genes. People with certain changes in the BRCA1 or BRCA2 genes are at increased risk of getting cancer, including breast and ovarian cancers. The names BRCA1 and BRCA2 stand for breast cancer susceptibility gene 1 and breast cancer susceptibility gene 2, respectively.

**CA-125:** A protein that may be found in high amounts in the blood of patients with certain types of cancer, including ovarian cancer. It may also be found in high amounts when other non-cancerous conditions are present, such as endometriosis, ovarian cysts, and uterine fibroids. CA-125 levels may also help track how well cancer treatments are working or if cancer has come back.

**Cell:** The basic unit that makes up all living things.

**Cervix (SUR-viks):** The lower, narrow end of the uterus that forms a canal between the uterus and vagina.

**DES or Diethylstilbestrol (die-eth-il-still-BES-stroll):** A man-made form of the hormone estrogen that was prescribed to pregnant women between about 1940 and 1971 because it was thought to prevent miscarriages. Doctors stopped using DES because it was found to be unsafe.

**Diagnosis (DY-ug-NOH-sis):** The process of identifying a disease based on its signs and symptoms, and medical testing.

**Endometriosis (END-oh-mee-tree-oh-sis):** A condition where tissue from the lining of the uterus grows elsewhere in the body.

**Estrogen (ES-troh-jin):** A type of hormone made by the body that helps women develop and maintain female sex traits. Man-made forms of estrogen may be used as a type of birth control and to treat symptoms of menopause, disorders related to a woman’s period, and other conditions.

**Fibroids (FY-broyd):** A non-cancerous tumor, commonly in the uterus.

**Follow-up:** Visits with your doctor for more testing or treatment.

**Gene (jeen):** The basic unit of heredity that holds information to build and maintain cells and pass genetic traits from parent to child.


Hereditary nonpolyposis colon cancer (her-ED-it-ayr-ee nahn-pah-lip-OH-sis KOHL-uhhn KAN-ser): A disorder inherited through one’s parents that causes a higher-than-normal chance of developing colorectal cancer and certain other types of cancer, including uterine and ovarian cancers, often before the age of 50. Also called Lynch syndrome.

HIV or Human immunodeficiency virus (HYOO-mun im-YUH-noh-di-fish-uhn-see VYE-rus): The virus that causes AIDS, which increases one’s risk for developing certain cancers and infections by making one less able to fight off health problems.

HPV or Human papillomavirus (HYOO-mun pap-ah-LO-mah-VYE-rus): A very common virus passed on during sex that can cause changes to cells. At least 50 percent of sexually active men and women will have HPV at some point in their lives. Most of the time, people who become infected with HPV will not have any symptoms and the infection will clear up on its own. However, when the infection does not clear up, it can cause normal cells to turn abnormal. Over time, these abnormal cells can turn into cancer of the cervix, vagina, or vulva.

HPV test: A test where a doctor swabs the cervix for cells and then examines them to look for HPV. This is often done at the same time as a Pap test for women aged 30 years and older. It also is used to provide more information when a Pap test has unclear results.

Hysterectomy (HIS-teh-REK-toh-mee): Surgery to remove the uterus and, generally, the cervix. When only the uterus is removed, it is called a partial hysterectomy. When the cervix also is removed, it is called a total hysterectomy.

Menopause (MEH-noh-PAWZ): The time of life when a woman’s menstrual periods stop. A woman is in menopause when she hasn’t had a period for 12 months in a row. Menopause, on average, happens between the ages of 45 and 55 years old or when a woman has her ovaries removed.

Ovaries (OH-vereez): Pair of female reproductive glands where the ova, or eggs, are formed. The ovaries are located in the pelvis—one on each side of the uterus. Ovaries produce the hormones estrogen and progesterone.

Pap test: A screening test where a doctor swabs the cervix for cells and then examines them under a microscope to look for changes on the cervix and early signs of cervical cancer, as well as precancerous changes on the cervix that can be treated. Cervical cancer is the only cancer that the Pap test screens for. It does NOT screen for ovarian, uterine, vaginal, or vulvar cancers.

Pelvis (PEL-vis): The area below the stomach and in between the hip bones.
Pelvic exam (PEL-vik ex-am): An exam to check the health of female reproductive organs. This exam may be part of a woman’s routine health care visit. Your doctor will look at the outside of your genitals, or sex organs, to see if there are any problems. He or she also will look at and feel your internal organs—such as your vagina, cervix, ovaries, and uterus. It may include a rectovaginal exam.

Precancer (PRE-KAN-ser): Cell changes that are not normal, but have not yet turned into cancer.

Progesterone (proh-JES-tuh-RONE): A type of hormone made by the body that plays a role in the menstrual cycle and pregnancy. Progesterone also can be made in the laboratory. It may be used as a type of birth control and to treat disorders related to a woman’s period, infertility, symptoms of menopause, and other conditions.

Rectovaginal exam (REK-toh-VA-jih-nul ex-am): An exam that is sometimes given along with a pelvic exam to check for problems, especially in the uterus or ovaries. A doctor will feel internal organs through the vagina and rectum (the last several inches of the large intestine closest to the anus) with one hand while touching the pelvis with the other hand.

Screening: Checking for disease when there are no symptoms. Cancer screening tests are effective when they can find disease early.

Transvaginal ultrasound (tranz-VA-jih-nul UL-truh-SOWND): A test used to check the uterus, fallopian tubes, ovaries, and bladder for problems. A wand is inserted into the vagina that causes sound waves to bounce off organs inside the pelvis, creating a picture called a sonogram. Also called transvaginal sonography and TVS.

Tubal ligation (TOO-bull lye-GAY-shun): An operation to close the fallopian tubes. This procedure prevents pregnancy by blocking the passage of eggs from the ovaries to the uterus.

Uterus (YOO-tuh-rus): The small, hollow, pear-shaped organ in a woman’s pelvis. This is the organ in which a baby grows. Also called the womb.

Vagina (vuh-JY-nuh): The muscular canal extending from the uterus to the exterior of the body. Also called the birth canal.

Vulva (vuhl-vuh): The external female genital organs, including the clitoris, labia (vaginal lips), and the opening to the vagina.
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