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**EASY READING**

# If You Have Uterine Sarcoma

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## What is a uterine sarcoma?

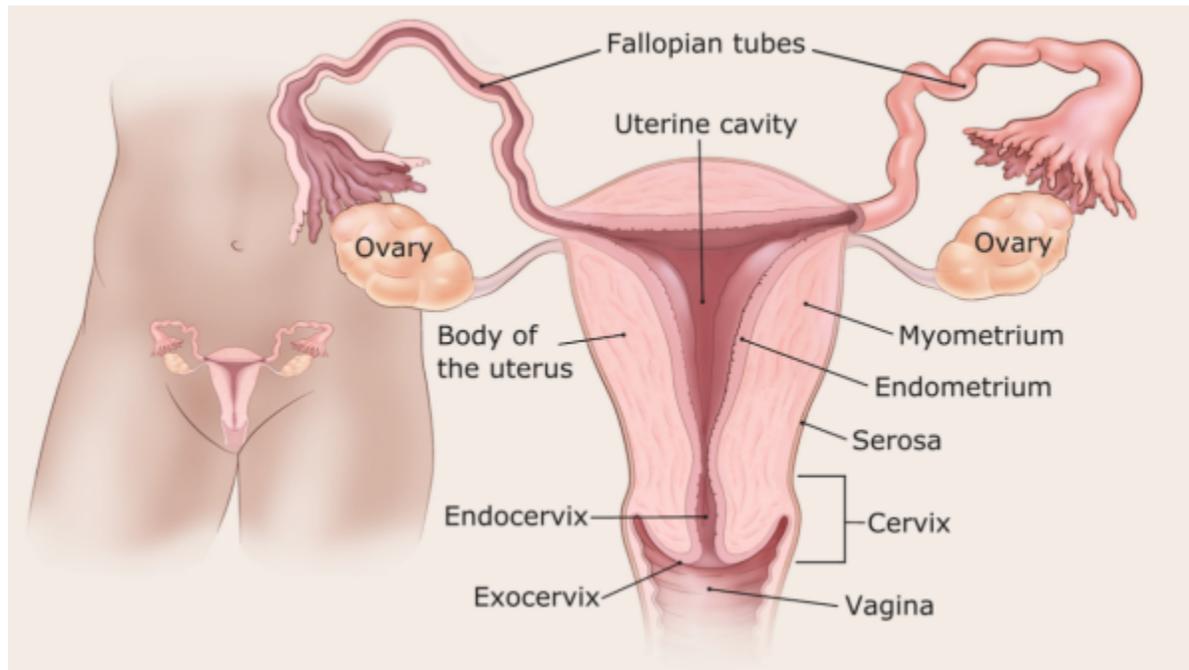
Cancer can start any place in the body. Cancer that starts in the muscle wall or the tissue that supports the uterus is called [uterine sarcoma](#)<sup>1</sup>. It starts when these cells grow out of control and crowd out normal cells.

Uterine sarcoma is rare. Many people are really talking about [endometrial cancer](#)<sup>2</sup> (en-doe-ME-tree-ul) when they say uterine cancer. This cancer is much more common. It starts in the lining of the uterus. It's not the same as uterine sarcoma.

Cancer cells can spread to other parts of the body. Sarcoma cells in the uterus can sometimes travel to lungs or the bone and grow there. When cancer cells do this, it's called metastasis (pronounced meh-TAS-tuh-sis). To doctors, the cancer cells in the new place look just like the ones from the uterine sarcoma.

Cancer is always named for the place where it starts, because when the cancer cells grow in a new place, they still look the same as the cells where the cancer started. So when uterine sarcoma spreads to the lung (or any other place), it's still called uterine

sarcoma. It's not called lung cancer unless it starts from cells in the lung.



**Ask your doctor to use these pictures to show you where your cancer is.**

### **Different kinds of uterine sarcoma**

There are several [types of uterine sarcoma](#)<sup>3</sup>. Each type is based on the kind of cell it starts in. The most common type of uterine sarcoma is called uterine leiomyosarcoma. These cancers start in the cells that make up the part of the uterus muscle wall called the myometrium (my-o-ME-tree-um).

Your doctor can tell you more about the type you have.

### **Questions to ask the doctor**

- Why do you think I have cancer?
- Is there a chance I don't have cancer?
- Would you please write down the kind of cancer you think I might have?
- What will happen next?

### **How does the doctor know I have uterine sarcoma?**

Uterine sarcoma may not be found until a woman goes to the doctor because of new or unusual bleeding from the vagina .

The doctor will ask you questions about your health and do a physical and a pelvic exam. If [signs](#)<sup>4</sup> are pointing to uterine sarcoma, more tests will be done. Here are some of the [tests you may need](#)<sup>5</sup>:

**Endometrial biopsy**<sup>6</sup> : In this test, the doctor takes out a small piece of the lining of the uterus (the endometrium) to check it for cancer cells. A very thin tube is put through the vagina into the uterus. Then a small piece of the endometrium is sucked out through the tube. A biopsy is the only way to tell for sure if you have cancer.

**Hysteroscopy** : A tiny telescope is put through the vagina to see into the uterus. The uterus is filled with salt water so the doctor can see it better. This lets the doctor find changes and take out anything that shouldn't be there. Numbing medicine is used to do this test, but the woman is awake.

**Dilation and curettage or D&C**: This test may be needed if the biopsy sample doesn't get enough tissue, or the results are not clear. To do this, the opening to the uterus (called the cervix) is opened and a special tool is used to scrape tissue from the endometrium. Drugs may be used to help you sleep during this test.

**Transvaginal ultrasound**<sup>7</sup> (TVUS): For this test, a small wand is put into the vagina. It gives off sound waves and picks up the echoes as they bounce off tissues. The echoes are made into a picture on a computer screen. These pictures can help see if cancer is growing into the muscle layer of the uterus. (This layer is called the myometrium. )

**CT scan**<sup>8</sup>: This is also called a CAT scan. It's a special kind of x-ray that takes detailed pictures to see if the cancer has spread to nearby lymph nodes.

**Chest x-rays**<sup>9</sup>: X-rays may be done to see if the cancer has spread to the lungs.

**PET scan**<sup>10</sup>: In this test, you are given a special type of sugar that can be seen inside your body with a special camera. If there is cancer, this sugar shows up as "hot spots" where the cancer is found. This test is useful when your doctor thinks the cancer might have spread, but doesn't know where.

**Blood tests**: Certain blood tests can tell the doctor more about your overall health.

### Questions to ask the doctor

- What tests will I need to have?

- Who will do these tests?
- Where will they be done?
- Who can explain them to me?
- How and when will I get the results?
- Who will explain the results to me?
- What do I need to do next?

## How serious is my cancer?

If you have uterine sarcoma, the doctor will want to find out how far it has spread. This is called [staging](#)<sup>11</sup>. You may have heard other people say that their cancer was “stage 1” or “stage 2.” Your doctor will want to find out the stage of your cancer to help decide what type of treatment is best for you.

The stage describes the growth or spread of the cancer in the place it started. It also tells if the cancer has spread to other parts of your body that are close by or farther away.

Your cancer can be stage 1, 2, 3, or 4. The lower the number, the less the cancer has spread. A higher number, like stage 4, means a more serious cancer that has spread from where it started. Be sure to ask the doctor about the cancer stage and what it means for you.

## Questions to ask the doctor

- Do you know the stage of the cancer?
- If not, how and when will you find out the stage of the cancer?
- Would you explain to me what the stage means in my case?
- Based on the stage of the cancer, how long do you think I'll live?
- What will happen next?

## What kind of treatment will I need?

There are many [ways to treat uterine sarcoma](#)<sup>12</sup>, but the main types of treatment are local or systemic.

Surgery and radiation are used to treat only the cancer. They do not affect the rest of

the body. This is called *local treatment*.

Chemo drugs go through the whole body. They can reach cancer cells anywhere in the body. This is called *systemic treatment*.

The treatment plan that's best for you will depend on:

- Where the cancer is
- The stage of the cancer
- The chance that a type of treatment will cure the cancer or help in some way
- Your age
- Other health problems you have
- Your feelings about the treatment and the [side effects](#)<sup>13</sup> that come with it

## **Surgery for uterine sarcoma**

[Surgery](#)<sup>14</sup> is the most common way to treat uterine sarcoma. It's used to take out all the cancer. In most cases, this means the uterus is removed. This is called a hysterectomy. There are many ways to do this surgery. Sometimes the ovaries and fallopian tubes are taken out at the same time. Nearby [lymph nodes](#)<sup>15</sup> may also be taken out to see if they contain cancer cells.

Ask your doctor what kind of surgery you will need. Each type has pros and cons.

### ***Side effects of surgery***

Any type of surgery can have risks and side effects. Ask the doctor what you can expect. If you have problems, let your doctors know. Doctors who treat people with uterine sarcoma should be able to help you with any problems that come up.

## **Radiation treatments**

[Radiation](#)<sup>16</sup> uses high-energy rays (like x-rays) to kill cancer cells. There are 2 main ways radiation can be given.

- **Vaginal brachytherapy:** With this method, radioactive seeds are put into a small tube that's put in the vagina. Brachytherapy does not affect nearby organs like the bladder or rectum as much as external radiation.
- **External radiation:** Getting this kind of radiation is a lot like getting a regular x-ray,

but it takes longer. It's most often given 5 days a week for 4 to 6 weeks. Treatments are quick, but the daily trips for treatment may be tiring.

### ***Side effects of radiation treatments***

If your doctor suggests radiation treatment, talk about what side effects you might have. Side effects depend on the type of radiation that's used. The most common side effects of radiation are:

- Skin changes where the radiation is given
- Feeling very tired (fatigue)
- Diarrhea
- Bladder problems
- Scars in the vagina

Most side effects get better after treatment ends. Some might last longer. Talk to your cancer care team about what you can expect.

### **Chemo**

[Chemo](#)<sup>17</sup> is the short word for chemotherapy – the use of drugs to fight cancer. The drugs may be given into a vein or taken as pills. These drugs go into the blood and spread through the body. Chemo is given in cycles or rounds. Each round of treatment is followed by a break. Most of the time, 2 or more chemo drugs are given. Treatment often lasts for many months.

### ***Side effects of chemo***

Chemo can make you feel very tired, sick to your stomach, and cause your hair to fall out. But most chemo side effects go away over time after treatment ends.

There are ways to treat most chemo side effects. If you have side effects, talk to your cancer care team so they can help.

### **Clinical trials**

Clinical trials are research studies that test new drugs or other treatments in people. They compare standard treatments with others that may be better.

If you would like to be in a clinical trial, start by asking your doctor if your clinic or hospital conducts clinical trials. See [Clinical Trials](#)<sup>18</sup> to learn more.

Clinical trials are one way to get state-of-the-art cancer treatment. They are the best way for doctors to find better ways to treat cancer. If your doctor can find one that's studying the kind of cancer you have, it's up to you whether to take part. And if you do sign up for a clinical trial, you can always stop at any time.

### **What about other treatments I hear about?**

When you have cancer you might hear about other ways to treat the cancer or treat your symptoms. These may not always be standard medical treatments. These treatments may be [vitamins, herbs, special diets, and other things](#)<sup>19</sup>. You may wonder about these treatments.

Some of these are known to help, but many have not been tested. Some have been shown not to help. A few have even been found to be harmful. Talk to your doctor about anything you're thinking about using, whether it's a vitamin, a diet, or anything else.

### **Questions to ask the doctor**

- What treatment do you think is best for me?
- What's the goal of this treatment? Do you think it could cure the cancer?
- Will treatment include surgery? If so, who will do the surgery?
- What will the surgery be like?
- What will I look like after surgery?
- How will my body work after surgery?
- Will I need other types of treatment, too?
- What's the goal of these treatments?
- Will treatment affect my sex life?
- Will I be able to get pregnant after treatment?
- What side effects could I have from these treatments?
- What can I do about side effects that I might have?
- Is there a clinical trial that might be right for me?
- What about special vitamins or diets that friends tell me about? How will I know if they are safe?
- How soon do I need to start treatment?
- What should I do to be ready for treatment?
- Is there anything I can do to help the treatment work better?

- What's the next step?

## What will happen after treatment?

You'll be glad when [treatment is over](#)<sup>20</sup>. But it's hard not to worry about cancer coming back. Even when cancer never comes back, people still worry about it. For years after treatment ends, you will see your cancer doctor. Be sure to go to all of these follow-up visits. You will have exams, blood tests, and maybe other tests to see if the cancer has come back.

At first, your visits may be every few months. Then, the longer you're cancer-free, the less often the visits are needed. Scope exams, lab tests, or imaging tests (like MRI or CT scans) may be done to look for signs of uterine sarcoma or treatment side effects. Your doctor will tell you which tests should be done and how often based on the stage of your cancer and the type of treatment you had.

Having cancer and dealing with treatment can be hard, but it can also be a time to look at your life in new ways. You might be thinking about how to improve your health. Call us or talk to your doctor to find out what you can do to feel better.

You can't change the fact that you have cancer. What you can change is how you live the rest of your life – making healthy choices and feeling as well as you can.

## Hyperlinks

1. [www.cancer.org/cancer/uterine-sarcoma/about/what-is-uterine-sarcoma.html](http://www.cancer.org/cancer/uterine-sarcoma/about/what-is-uterine-sarcoma.html)
2. [www.cancer.org/cancer/endometrial-cancer/about/what-is-endometrial-cancer.html](http://www.cancer.org/cancer/endometrial-cancer/about/what-is-endometrial-cancer.html)
3. [www.cancer.org/cancer/uterine-sarcoma/about/what-is-uterine-sarcoma.html](http://www.cancer.org/cancer/uterine-sarcoma/about/what-is-uterine-sarcoma.html)
4. [www.cancer.org/cancer/uterine-sarcoma/detection-diagnosis-staging/signs-symptoms.html](http://www.cancer.org/cancer/uterine-sarcoma/detection-diagnosis-staging/signs-symptoms.html)
5. [www.cancer.org/cancer/uterine-sarcoma/detection-diagnosis-staging/how-diagnosed.html](http://www.cancer.org/cancer/uterine-sarcoma/detection-diagnosis-staging/how-diagnosed.html)
6. [www.cancer.org/treatment/understanding-your-diagnosis/tests/testing-biopsy-and-cytology-specimens-for-cancer.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/testing-biopsy-and-cytology-specimens-for-cancer.html)
7. [www.cancer.org/treatment/understanding-your-diagnosis/tests/ultrasound-for-cancer.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/ultrasound-for-cancer.html)
8. [www.cancer.org/treatment/understanding-your-diagnosis/tests/ct-scan-for-cancer.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/ct-scan-for-cancer.html)

9. [www.cancer.org/treatment/understanding-your-diagnosis/tests/x-rays-and-other-radiographic-tests.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/x-rays-and-other-radiographic-tests.html)
10. [www.cancer.org/treatment/understanding-your-diagnosis/tests/nuclear-medicine-scans-for-cancer.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/nuclear-medicine-scans-for-cancer.html)
11. [www.cancer.org/cancer/uterine-sarcoma/detection-diagnosis-staging/staging.html](http://www.cancer.org/cancer/uterine-sarcoma/detection-diagnosis-staging/staging.html)
12. [www.cancer.org/cancer/uterine-sarcoma/treating.html](http://www.cancer.org/cancer/uterine-sarcoma/treating.html)
13. [www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html](http://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html)
14. [www.cancer.org/cancer/uterine-sarcoma/treating/surgery.html](http://www.cancer.org/cancer/uterine-sarcoma/treating/surgery.html)
15. [www.cancer.org/cancer/cancer-basics/lymph-nodes-and-cancer.html](http://www.cancer.org/cancer/cancer-basics/lymph-nodes-and-cancer.html)
16. [www.cancer.org/cancer/uterine-sarcoma/treating/radiation-therapy.html](http://www.cancer.org/cancer/uterine-sarcoma/treating/radiation-therapy.html)
17. [www.cancer.org/cancer/uterine-sarcoma/treating/chemotherapy.html](http://www.cancer.org/cancer/uterine-sarcoma/treating/chemotherapy.html)
18. [www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html](http://www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html)
19. [www.cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine.html](http://www.cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine.html)
20. [www.cancer.org/treatment/survivorship-during-and-after-treatment.html](http://www.cancer.org/treatment/survivorship-during-and-after-treatment.html)
21. <http://www.cancer.org>

## Words to know

**Biopsy** (BY-op-see): Taking out a small piece of tissue to see if there are cancer cells in it.

**Endometrium** (en-doe-ME-tree-um): The lining of the womb (uterus).

**Fallopian** (fuh-LO-pee-in) **tube**: the tube that carries an egg from the ovary to the uterus. There are 2 of them.

**Lymph nodes** (limf nodes): Small, bean-shaped sacs of immune system tissue found all over the body and connected by lymph vessels; also called lymph glands.

**Metastasis** (muh-TAS-tuh-sis): Cancer cells that have spread from where they started to other places in the body.

**Myometrium** (my-o-ME-tree-um): The thick muscle layer of the uterus that's needed to push a baby out during childbirth.

**Ovary** (O-vuh-ree): Reproductive organ in the female pelvis. Normally a woman has 2 ovaries. They contain the eggs (ova) that, when joined with sperm, can result in pregnancy.

**Sarcoma** (sar-KO-muh): Cancer that starts in connective tissue, such as cartilage, fat, muscle, or bone.

**Uterus** (YEW-tuh-rus): Also called the womb. The pear-shaped organ in a woman's pelvis that holds a growing baby.

**Vagina** (vuh-JIE-nuh): The passage leading from the vulva (the female genital organs that are on the outside of the body) to the uterus (the womb).

### How can I learn more?

We have a lot more information for you. You can find it online at [www.cancer.org](http://www.cancer.org) (<http://www.cancer.org>)<sup>21</sup>. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

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Our team is made up of doctors and oncology certified nurses with deep knowledge of cancer care as well as journalists, editors, and translators with extensive experience in medical writing.

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