Uterine Sarcoma Early Detection, Diagnosis, and Staging

Detection and Diagnosis

Catching cancer early often allows for more treatment options. Some early cancers may have signs and symptoms that can be noticed, but that is not always the case.

- Can Uterine Sarcoma Be Found Early?
- Signs and Symptoms of Uterine Sarcomas
- Tests for Uterine Sarcoma

Stages and Outlook (Prognosis)

After a cancer diagnosis, the stage gives important information about the spread of cancer in the body and likely response to treatment.

- Uterine Sarcoma Stages
- Survival Rates for Uterine Sarcoma

Questions to Ask About Uterine Sarcoma

Here are some questions you can ask your cancer care team to help you better understand your cancer diagnosis and treatment options.

- Questions to Ask About Uterine Sarcoma
Can Uterine Sarcoma Be Found Early?

Sometimes, knowing the signs and symptoms of uterine sarcoma and seeing a health care professional right away can help find it at an early stage (when it’s small and hasn’t spread). But many uterine sarcomas reach an advanced stage before signs and symptoms appear.

Screening tests

Screening refers to testing to find a disease, such as cancer, in people who don’t have symptoms of the disease. At this time, there are no screening tests or exams to find uterine sarcomas in women without symptoms. Screening tests used for cervical cancer, such as a Pap test or HPV (human papillomavirus) test aren’t effective for uterine sarcomas.

Still, the Pap test is very good at finding early cancers of the cervix (the lower part of the uterus). For information on finding cervical cancer early, see Cervical Cancer Screening Guidelines¹.

Hyperlinks


References


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Sarcomas

Certain symptoms might suggest you have a uterine sarcoma. But these symptoms don't always mean that a woman has uterine sarcoma. More often they are caused by something else, such as non-cancerous changes in the uterus (like fibroids), pre-cancer overgrowth of the endometrium, or endometrial carcinoma. Still, if you're having these problems, see a doctor as soon as possible to find the cause and get any needed treatment.

Abnormal bleeding or spotting

Most people diagnosed with uterine sarcomas have abnormal bleeding (bleeding between periods, more bleeding during periods, or bleeding after menopause). This symptom is more often caused by conditions other than cancer, but it's important to have any abnormal bleeding checked right away.

If you've gone through menopause, any vaginal bleeding or spotting is abnormal, and should be reported to your health care professional right away.

Vaginal discharge

Some women with uterine sarcomas have a vaginal discharge that does not have any blood. A discharge is most often a sign of infection or another non-cancer condition, but it also can be a sign of cancer. Any abnormal discharge should be checked by a health care provider.

Pain and/or a mass

Some women with uterine sarcomas might have pain in the pelvis or the abdomen and/or a mass (lump) that can be felt. You or your doctor may be able to feel the mass in your uterus, or you might have a feeling of fullness in your belly and/or pelvis.

Urine or bowel problems

A mass in the pelvis might push on the bladder which can cause you to urinate (pee) more often than usual. It might also disturb the bowels and cause constipation.

Hyperlinks

**References**


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**Tests for Uterine Sarcoma**

If you have symptoms of uterine sarcoma, the first step is to see your doctor.

**Medical history and physical exam**

Your doctor will ask you about your personal and family medical history. You also will be asked about any symptoms, risk factors, and other health problems. A general physical and a pelvic exam will be done to check if the uterus is larger than normal.

If your doctor suspects cancer based on your symptoms and/or exam, you may be told you need other tests and also be referred to a gynecologist or a doctor specializing in cancers of the female reproductive system (called a gynecologic oncologist).

**Tests to diagnose uterine sarcoma**
**Endometrial biopsy and tissue sampling**

To find the reason for the abnormal bleeding, a small piece of tissue will be taken from the lining of the uterus (endometrium) and looked at closely in the lab. The tissue can also be removed by dilation and curettage (D&C). See below for a description of how this is done.

These procedures let the doctor see if the bleeding is caused by an overgrowth of cells in the endometrium (hyperplasia) that's not cancer, endometrial carcinoma, uterine sarcoma, or some other problem. The tests will find endometrial stromal sarcomas, but not as many leiomyosarcomas (LMSs).

These tests don't find LMSs as often because these cancers start in the muscle layer of the wall of the uterus, not the inner lining. To be found by an endometrial biopsy or D&C, LMSs need to have spread from the middle (muscle) layer to the inner lining of the uterus. In most cases, the only way to diagnose a LMS is by removing it with surgery. Many uterine sarcomas are diagnosed during or after surgery for what's thought to be benign fibroid tumors.

**Endometrial biopsy**

In this procedure, a very thin, flexible tube is put into the uterus through the cervix. Then, using suction, a small sample or amount of the uterine lining (endometrium) is taken out through the tube. Suctioning takes about a minute or less and may be done more than once to get enough tissue. The discomfort is a lot like severe menstrual cramps and can be helped by taking a nonsteroidal anti-inflammatory drug like ibuprofen an hour before the biopsy, if approved by your doctor. This procedure is usually done in the doctor's office.

**Hysteroscopy**

This procedure allows doctors to look inside the uterus. A thin long camera (called a hysteroscope) that is either soft and flexible or rigid is put into the uterus through the cervix. To get a better view, the uterus is then expanded by filling it with salt water (saline) or gas. This lets the doctor see and take out anything that looks abnormal, such as a cancer or a polyp, or take a tissue sample (biopsy). If the doctor is just taking a look, this procedure can be done with the patient awake, using local anesthesia (numbing medicine). But if a lot of tissue, a polyp, or a mass has to be removed, general or regional anesthesia is used. (General anesthesia means you are given drugs that put you into a deep sleep and keep you from feeling pain. Regional anesthesia is a nerve block that numbs one area of the body).
Dilation and curettage (D & C)

If an endometrial biopsy is not possible or the results of the endometrial biopsy are not clear (meaning they can't tell for sure if there is cancer), a procedure called dilation and curettage (D&C) is usually done. A D&C is a surgical procedure that is usually done in the outpatient surgery area of a clinic or hospital. It's done while the woman is under general or regional anesthesia or conscious sedation (medicine is given into a vein to make her drowsy). In a D&C, the cervix is dilated (opened) and a special surgical tool is used to remove the endometrial tissue from inside the uterus so it can be checked in the lab. A hysteroscopy may be done as well. Some women have mild-to-moderate cramping and discomfort after this procedure.

Cystoscopy and proctoscopy

If a woman has signs or symptoms that suggest uterine sarcoma has spread to the bladder or rectum, imaging can help to confirm this. Rarely, a camera or lighted tube might be used to look inside of these organs. These exams are called cystoscopy (to look in the bladder) and proctoscopy (to look in the rectum), and might be done only if imaging is not helpful.

Lab tests of biopsy and other samples

Any tissue or biopsy samples are looked at closely in the lab to see if there is cancer. If cancer is found, the lab report will say if it's a carcinoma or sarcoma, what type it is, and its grade.

Tumor grade

Cancer cells are given a grade when they are removed from the body and checked in the lab. The grade is based on how much the cancer cells look like normal cells. The grade is used to help predict your outcome (prognosis) and to help figure out what treatments might work best.

- A low-grade number usually means the cancer is slower-growing and less likely to spread.
- A high-grade number means a faster-growing cancer that’s more likely to spread.

For example, high-grade sarcomas tend to grow and spread faster than low-grade sarcomas.
Hormone receptor status

The tissue sample or biopsy might also be tested to see if the cancer cells have estrogen receptors and progesterone receptors. These hormone receptors are found on many endometrial stromal sarcomas and some leiomyosarcomas. Cancers with estrogen receptors are more likely to grow with estrogen, while those with progesterone receptors often don't grow if exposed to progesterone. These cancers may stop growing (or even shrink) when treated with certain hormone drugs. Hormone drugs may also be used to prevent the cancer from coming back after initial treatment (recurrence) if the cancer is found to have estrogen or progesterone receptors. Checking for these receptors helps predict which cancers might benefit from hormone treatment.

Imaging tests

Transvaginal ultrasound

Ultrasound tests use sound waves to take pictures of parts of the body. For a transvaginal ultrasound, a probe that gives off sound waves is put into the vagina. The sound waves are used to make images of the uterus and other pelvic organs. These images can often show if there's a tumor or lump and if it invades the myometrium (muscle layer of the uterus).

For a sonohysterogram or saline infusion sonogram, salt water (saline) is put into the uterus through a small tube before or during the transvaginal ultrasound. This lets the doctor see changes in the uterine lining more clearly.

Computed tomography

The CT scan is an x-ray test that makes detailed cross-sectional images of your body. CT scans are rarely used to diagnose uterine sarcoma, but they might be helpful in seeing if the cancer has spread to other organs.

CT-guided needle biopsy: CT scans can also be used to guide a biopsy needle exactly into an abnormal area or tumor. For this procedure, the patient remains on the CT scanning table while the doctor moves a biopsy needle through the skin and toward the tumor. CT scans are repeated until the needle is inside the tumor. A needle biopsy sample is then removed and looked at closely in the lab. This isn’t done to biopsy tumors inside the uterus, but might be used to biopsy areas that look like metastasis (cancer spread).

Magnetic resonance imaging
MRI scans\(^7\) also make cross-section pictures of your insides but use radio waves and strong magnets instead of x-rays. An MRI scan can help tell if a uterine tumor looks like cancer, but a biopsy is still needed to tell for sure. It can also help find out if any cancer has been left behind after surgery or if the cancer has grown into nearby structures which can help in making a treatment plan.

MRI scans are also very helpful in looking for cancer that has spread to the brain and spinal cord.

**Positron emission tomography scan**

In a PET scan\(^8\), a slightly radioactive form of sugar (known as FDG) is injected into the blood and collects mainly in cancer cells.

**PET/CT scan:** Often a PET scan is combined with a CT scan using a special machine that can do both at the same time. This lets the doctor compare areas of higher radioactivity on the PET scan with a more detailed picture on the CT scan.

PET/CT scans can be useful for patients with uterine sarcomas, if your doctor thinks the cancer might have spread but doesn’t know where.

**Chest x-ray**

An x-ray of the chest might be done to see if a uterine sarcoma has spread to the lungs and as part of the testing before surgery. If something suspicious is seen, your doctor may order more tests.

**Hyperlinks**

5. [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)
7. [www.cancer.org/treatment/understanding-your-diagnosis/tests/mri-for-cancer.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/mri-for-cancer.html)
8. [www.cancer.org/treatment/understanding-your-diagnosis/tests/nuclear-medicine-](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/nuclear-medicine-
Uterine Sarcoma Stages

After a woman is diagnosed with uterine sarcoma, doctors will try to figure out if it has spread, and if so, how far. This process is called staging. The stage of a cancer describes the amount of cancer spread in the body and helps determine how best to treat it. Doctors also use a cancer’s stage when talking about survival statistics.

Uterine sarcoma stages range from stage I (1) through IV (4). As a rule, the lower the number, the less the cancer has spread. A higher number, such as stage IV, means cancer has spread more. And sometimes, a stage might be divided further using letters.
An earlier letter means a lower stage. Although each person’s cancer experience is unique, cancers with similar stages tend to have a similar outlook and are often treated in much the same way.

How is the stage determined?

The systems used to stage uterine sarcoma, the FIGO (International Federation of Gynecology and Obstetrics) system and the (AJCC) American Joint Committee on Cancer TNM staging system are basically the same.

They both stage (classify) this cancer based on 3 factors:

- The extent (size) of the tumor (T): How large is the cancer? Has the cancer grown out of the uterus into the pelvis or organs such as the bladder or rectum?
- The spread to nearby lymph nodes (N): Has the cancer spread to nearby lymph nodes?
- The spread (metastasis) to distant sites (M): Has the cancer spread to distant lymph nodes or organs?

Numbers or letters after T, N, and M provide more details about each of these factors. Higher numbers mean the cancer is more advanced. Once a person’s T, N, and M categories have been determined, this information is combined in a process called stage grouping to assign an overall stage.

The staging system in the table below uses the pathologic stage (also called the surgical stage). It is determined by examining tissue removed during an operation. Sometimes, if surgery is not possible, the cancer will be given a clinical stage instead. This is based on the results of a physical exam, biopsy, and imaging tests done without surgery. For more information see Cancer Staging.

The system described below is the most recent AJCC system, effective January 2018. It is only for staging leiomyosarcoma and endometrial stromal sarcoma.

Uterine sarcoma staging can be complex, so ask your doctor to explain it to you in a way you understand.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Stage grouping</th>
<th>FIGO Stage</th>
<th>Stage description*</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>I1</td>
<td>I</td>
<td>The cancer is growing in the uterus, but has not started growing outside the uterus. It has not spread to nearby lymph nodes (N0) or</td>
</tr>
<tr>
<td>Stage</td>
<td>T</td>
<td>N</td>
<td>M</td>
</tr>
<tr>
<td>-------</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>IA</td>
<td>T1a</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>IB</td>
<td>T1b</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>II</td>
<td>T2</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>IIIA</td>
<td>T3a</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>IIIB</td>
<td>T3b</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>IIIC</td>
<td>T1-T3</td>
<td>N1</td>
<td>M0</td>
</tr>
<tr>
<td>IVA</td>
<td>T4</td>
<td>Any N</td>
<td>M0</td>
</tr>
</tbody>
</table>
Any T  Any N  M1  IVB
The cancer has spread to distant sites such as the lungs, bones, or liver (M1). The cancer in the uterus can be any size and may or may not have grown into tissues in the pelvis and/or abdomen (including the bladder or rectum) (any T) and it might or might not have spread to nearby lymph nodes (Any N).

* The following additional categories are not listed on the table above:

- **TX:** Main tumor cannot be assessed due to lack of information.
- **T0:** No evidence of a primary tumor.
- **NX:** Regional lymph nodes cannot be assessed due to lack of information.

**Hyperlinks**

3. [www.cancer.org/treatment/understanding-your-diagnosis/staging.html](http://www.cancer.org/treatment/understanding-your-diagnosis/staging.html)

**References**


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**Survival Rates for Uterine Sarcoma**

Survival rates can give you an idea of what percentage of people with the same type and stage of cancer are still alive a certain amount of time (usually 5 years) after they were diagnosed. They can’t tell you how long you will live, but they may help give you a
better understanding of how likely it is that your treatment will be successful.

Keep in mind that survival rates are estimates and are often based on previous outcomes of large numbers of people who had a specific cancer, but they can’t predict what will happen in any particular person’s case. These statistics can be confusing and may lead you to have more questions. Your doctor is familiar with your situation; ask how these numbers may apply to you.

What is a 5-year relative survival rate?

A relative survival rate compares people with the same type and stage of uterine sarcoma to people in the overall population. For example, if the 5-year relative survival rate for a specific stage of uterine sarcoma is 90%, it means that people who have that cancer are, on average, about 90% as likely as people who don’t have that cancer to live for at least 5 years after being diagnosed.

Where do these numbers come from?

The American Cancer Society relies on information from the Surveillance, Epidemiology, and End Results (SEER) database, maintained by the National Cancer Institute (NCI), to provide survival statistics for different types of cancer.

The SEER database tracks 5-year relative survival rates for uterine sarcoma in the United States, based on how far the cancer has spread. The SEER database, however, does not group cancers by FIGO or AJCC TNM stages (stage 1, stage 2, stage 3, etc.). Instead, it groups cancers into localized, regional, and distant stages:

- **Localized:** There is no sign the cancer has spread outside of the uterus.
- **Regional:** The cancer has spread outside the uterus to nearby structures or lymph nodes.
- **Distant:** The cancer has spread to distant parts of the body such as the lungs, liver, or bones.

5-year relative survival rates for uterine sarcoma

These numbers are based on women diagnosed with uterine sarcoma between 2011 and 2017. These survival rates differ based on type of uterine sarcoma\(^1\) (leiomyosarcoma, undifferentiated sarcoma, endometrial stromal sarcoma - low grade).
### Leiomyosarcoma

<table>
<thead>
<tr>
<th>SEER Stage</th>
<th>5-Year Relative Survival Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Localized</td>
<td>62%</td>
</tr>
<tr>
<td>Regional</td>
<td>34%</td>
</tr>
<tr>
<td>Distant</td>
<td>13%</td>
</tr>
<tr>
<td>All SEER stages combined</td>
<td>39%</td>
</tr>
</tbody>
</table>

### Undifferentiated sarcoma

<table>
<thead>
<tr>
<th>SEER Stage</th>
<th>5-Year Relative Survival Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Localized</td>
<td>68%</td>
</tr>
<tr>
<td>Regional</td>
<td>36%</td>
</tr>
<tr>
<td>Distant</td>
<td>21%</td>
</tr>
<tr>
<td>All SEER stages combined</td>
<td>43%</td>
</tr>
</tbody>
</table>

### Endometrial stromal sarcoma - low grade*

<table>
<thead>
<tr>
<th>SEER Stage</th>
<th>5-Year Relative Survival Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Localized</td>
<td>98%</td>
</tr>
<tr>
<td>Regional</td>
<td>95%</td>
</tr>
<tr>
<td>Distant</td>
<td>78%</td>
</tr>
<tr>
<td>All SEER stages combined</td>
<td>95%</td>
</tr>
</tbody>
</table>

*The outlook for high-grade endometrial stromal sarcoma tends to be much worse than for low-grade endometrial stromal sarcoma, and is more likely to be similar to that for undifferentiated sarcoma (see table above).

### Understanding the numbers

- **These numbers apply only to the stage of the cancer when it is first diagnosed.** They do not apply later on if the cancer grows, spreads, or comes back.
after treatment.

- **These numbers don’t take everything into account.** Survival rates are grouped based on how far the cancer has spread, but your age, overall health, tumor grade, tumor type\(^2\), how well the cancer responds to treatment, and other factors can also affect your outlook.

- **People being diagnosed with uterine sarcoma now may have a better outlook than these numbers show.** Treatments improve over time, and these numbers are based on people who were diagnosed and treated at least five years earlier.

**Hyperlinks**


**References**


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Questions to Ask About Uterine Sarcoma

It is important for you to have honest, open discussions with your cancer care team. They want to answer all of your questions to help you make informed treatment and life decisions. Here are some questions to consider.

When you’re told you have uterine sarcoma

- What type and grade of uterine sarcoma do I have?
- Has the cancer spread outside my uterus?
- What is the stage of my cancer and what does that mean for me?
- Do I need to see a specialist?
- What should I do to be ready for treatment?
- What risks or side effects should I expect?
- What are the chances my cancer will come back with the treatment options we have discussed?
- What is my prognosis (outlook), based on what you know about my cancer?

When deciding on a treatment plan

- What are my treatment choices?
- What treatment do you recommend and why?
- How much experience do you have treating this type of cancer?
- Should I get a second opinion? How do I do that? Can you recommend someone?
- Is there a clinical trial that you would recommend for me?
- What would the goal of the treatment be?
- How quickly do I need to decide on treatment?
- What should I do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- What risks or side effects are there to the treatments you suggest? Are there things I can do to reduce these side effects?
- How might treatment affect my daily activities?
- Will the treatment put me into menopause early?
- Will I need hormone replacement therapy after treatment? If so, is it safe? What are
the chances my cancer will recur (come back) with these treatment plans?
- What will we do if the treatment doesn’t work or if the cancer comes back?
- Will I be able to have children after my treatment?
- What are my treatment options if I want to have children in the future?

**During treatment**

Once treatment begins, you’ll need to know what to expect and what to look for. Not all of these questions may apply to you, but asking the ones that do may be helpful.

- How will we know if the treatment is working?
- Is there anything I can do to help manage side effects?
- What symptoms or side effects should I tell you about right away?
- How can I reach your team on nights, holidays, or weekends?
- Do I need to change what I eat during treatment?
- Are there limits on what I can do?
- Can I have sex during treatment? Will my sex life change after treatment?
- What kind of exercise should I do, and how often?
- Can you suggest a mental health professional I can see if I start to feel overwhelmed, depressed, or distressed?

**After treatment**

- Will I need a special diet after treatment?
- Are there any limits on what I can do?
- What other symptoms should I watch for?
- What kind of exercise should I do now?
- What type of follow-up will I need after treatment?
- How often will I need to have follow-up exams and imaging tests?
- Will I need any blood tests?
- How will we know if the cancer has come back? What should I watch for?
- What will my options be if the cancer comes back?

Along with these sample questions, be sure to write down some of your own. For example, you might want specific information about recovery times so that you can plan your work schedule.
Keep in mind that doctors aren’t the only ones who can give you information. Other health care professionals, such as nurses and social workers, can answer some of your questions. To find out more about speaking with your health care team, see The Doctor-Patient Relationship.6

Hyperlinks


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Written by

The American Cancer Society medical and editorial content team (www.cancer.org/cancer/acs-medical-content-and-news-staff.html)

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