



## UTERINE SARCOMA

### What is cancer?

The body is made up of hundreds of millions of living cells. Normal body cells grow, divide, and die in an orderly fashion. 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. 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 cell does.

People can inherit damaged DNA, but most 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.

In most cases the cancer cells form a tumor. Some cancers, like leukemia, rarely form tumors. Instead, these cancer cells involve the blood and blood-forming organs and circulate through other tissues where they grow.

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.

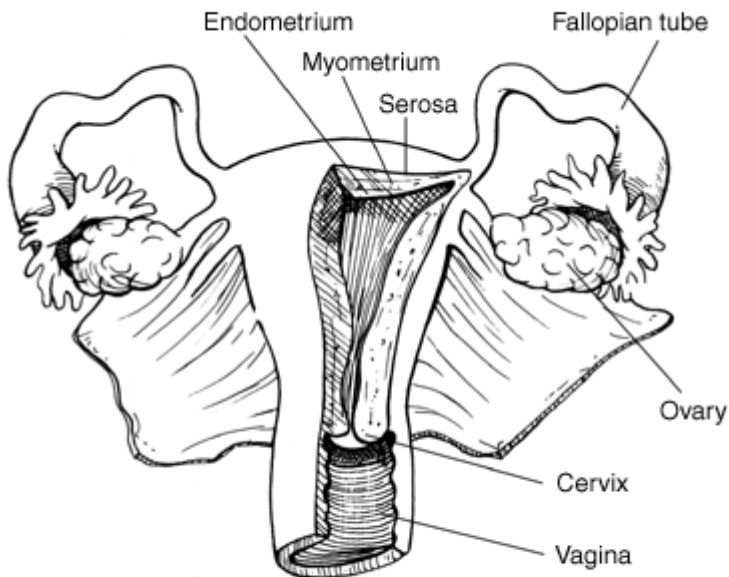
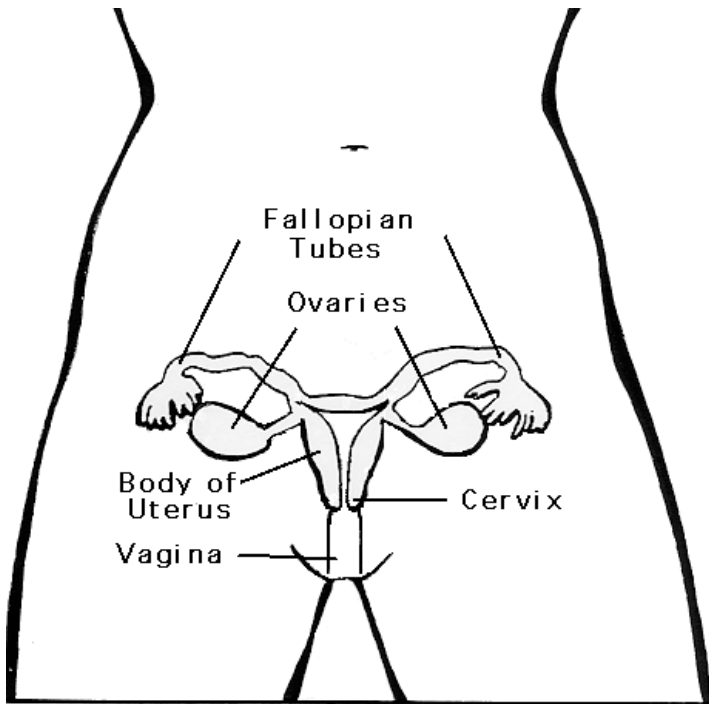
No matter where a cancer may spread, it is always named for the place where it started. For example, breast cancer that has spread to the liver is still called breast cancer, not liver cancer. Likewise, prostate cancer that has spread to the bone is metastatic prostate cancer, not bone cancer.

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 cannot 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 uterine sarcoma?**

Uterine sarcoma is a cancer of the muscle and supporting tissues of the uterus (womb).



## About the uterus

The uterus is a hollow organ, about the size and shape of a medium-sized pear. It has two main parts. The lower end of the uterus, which extends into the vagina, is called the cervix. The upper part of the uterus is called the body, and is also known as the *corpus*. The body of

the uterus has 3 layers. The inner layer or lining is called the *endometrium*. The *serosa* is the layer of tissue coating the outside of the uterus. In the middle is a thick layer of muscle that is also known as the *myometrium*. This muscle layer is needed to push the baby out during birth.

## Cancers of the uterus and endometrium

*Sarcomas* are cancers that start from tissues such as muscle, fat, bone, and fibrous tissue (the material that forms tendons and ligaments). Cancers that start in epithelial cells, the cells that line or cover most organs, are called *carcinomas*.

More than 95% of cancers of the uterus are carcinomas. If a carcinoma starts in the cervix, it is called a *cervical carcinoma*. Carcinomas starting in the endometrium, the lining of the uterus, are called *endometrial carcinomas*. These 2 cancers are discussed in our documents *Cervical Cancer* and *Endometrial Cancer*. This document is about *uterine sarcomas*.

Most uterine sarcomas fall into 1 of 2 categories, based on the type of cell they developed from:

- **Endometrial stromal sarcomas** develop in the supporting connective tissue (*stroma*) of the endometrium. These cancers are rare, representing a little over 1% of all uterine cancers. These tumors can be divided into 2 groups: low-grade and undifferentiated (high-grade). Low-grade endometrial stromal sarcomas tend to grow slowly - patients with these tumors have a better outlook than those with undifferentiated (high grade) tumors. Undifferentiated tumors are more aggressive and respond differently to treatment than low-grade tumors.
- **Uterine leiomyosarcomas** start in the muscular wall of the uterus known as the myometrium. These tumors make up about 2% of cancers that start in the uterus.

Another type of cancer that starts in the uterus is called carcinosarcoma. These cancers start in the endometrium and have features of both sarcomas and carcinomas. They can be classified with uterine sarcomas, but many doctors now believe they are more closely related to carcinomas. These cancers are also known as *malignant mixed mesodermal tumors* or *malignant mixed mullerian tumors*. Uterine carcinosarcomas are discussed in detail in the American Cancer Society document about endometrial cancer.

## Benign tumors

Several types of benign (non-cancerous) tumors can also develop in the connective tissues of the uterus. These tumors, such as leiomyomas, adenofibromas, and adenomyomas, are also known as *fibroid tumors*. Most of the time, these tumors require no treatment. Treatment may

be needed, however, if they start causing problems - such as pelvic pain, heavy bleeding, frequent urination, or constipation. In some cases, the tumor is removed, leaving the rest of the uterus in place; this surgery is called myomectomy. Some treatments can destroy these benign tumors without surgery, by blocking the blood vessels that feed them, by killing the tumor cells with electric current, or by freezing them with liquid nitrogen. Another option is to remove the entire uterus (surgery called a hysterectomy).

The rest of this document is about uterine sarcomas.

## **What are the key statistics about uterine sarcoma?**

The American Cancer Society's most recent estimates for cancer of the uterine corpus (body of the uterus) in the United States are for 2009:

- About 42,160 new cases of cancer of the uterine corpus will be diagnosed, but only about 1,200 of these cases will be uterine sarcomas.
- About 7,780 women in the United States will die from cancer of the uterine corpus during 2009.

Incidence rates of uterine sarcoma cancer have been decreasing since 1998 after a period of increase during the previous decade. Death rates from uterine sarcoma have been stable since 1992 after decreasing from 1975 to 1992.

## **What are the risk factors for uterine sarcoma?**

A risk factor is anything that changes your 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 the disease.

Only a few factors are known to change the risk of developing a uterine sarcoma.

## **Pelvic radiation therapy**

High-energy (ionizing) radiation used to treat some cancers can damage cell's DNA, sometimes increasing the risk of developing a second type of cancer. If you have had pelvic radiation, your risk for developing uterine sarcomas is increased. These cancers usually are diagnosed 5 to 25 years after exposure to the radiation.

## **Race**

Uterine sarcomas are about twice as common in African-American women as they are in white or Asian women. The reason for this increased risk is unknown.

Remember, however, that these factors increase the risk for developing some uterine sarcomas, but they may not always cause the disease.

## **Do we know what causes uterine sarcoma?**

It is not yet known exactly what causes most uterine sarcomas, but certain risk factors have been identified. A great deal of research is under way to learn more about the disease.

Scientists have recently learned much about changes in the DNA of certain genes that occur when normal uterine cells develop into sarcomas. Some of the observations are discussed in the section "What's new in uterine sarcoma research and treatment?"

## **Can uterine sarcoma be prevented?**

Most cases of uterine sarcoma cannot be prevented. Although pelvic radiation increases the risk of developing a uterine sarcoma, the benefit of pelvic radiation in treating other cancers far outweighs the risk of developing a rare cancer such as uterine sarcoma many years later.

## **Can uterine sarcoma be found early?**

In some cases, knowing the signs and symptoms of uterine sarcoma and discussing them promptly with your health care professional can help find it at an early stage. Unfortunately, many uterine sarcomas reach an advanced stage before recognizable signs and symptoms are present. The signs and symptoms for the 2 main types of uterine sarcoma are different.

## **Screening tests**

Screening refers to testing to find a disease such as cancer in people who do not have symptoms of that disease. At this time, there are no tests or exams to detect uterine sarcomas in women without symptoms (asymptomatic). The Pap test, which screens for cervical cancer, can occasionally find some early uterine sarcomas, but it is not a good test for this type of cancer.

The Pap test is very effective, however, in finding early carcinomas of the cervix (the lower part of the uterus). For information on screening tests for cervical cancer, see our document, *Cervical Cancer*.

## **How is uterine sarcoma diagnosed?**

In most cases, the possibility of uterine sarcoma is suggested by certain symptoms. These symptoms do not always mean that a woman has a uterine sarcoma. In fact, they are more often caused by something else, such as non-cancerous changes in the uterus, pre-cancerous overgrowth of the endometrium, or endometrial carcinoma. Doctors use one or more tests to make a diagnosis.

## **Signs and symptoms of uterine sarcomas**

### **Abnormal bleeding or spotting**

If you have gone through menopause, any vaginal bleeding or spotting is abnormal, and it should be reported to your health care professional right away. About 85% of patients diagnosed with uterine sarcomas have irregular vaginal bleeding (between periods) or bleeding after menopause. This symptom is more often caused by something besides cancer, but it is important to have a medical evaluation of any irregular bleeding right away. Of the uterine sarcomas, leiomyosarcomas are less likely to cause abnormal bleeding than endometrial stromal sarcomas.

### **Vaginal discharge**

About 10% of women with uterine sarcomas have a vaginal discharge (that does not contain any visible blood). A discharge is most often a sign of infection or another benign condition, but it also can be a sign of cancer. Any abnormal discharge should be investigated by your health care professional.

### **Pelvic pain and/or mass**

When they are first diagnosed, about 10% of women with uterine sarcomas have pelvic pain and/or a mass (tumor) that can be felt. You or your doctor may be able to feel the mass in your uterus, or you may have a feeling of fullness in your pelvis.

## **Consultation, medical history, and physical exam**

### **Consult with a specialist**

If a uterine cancer is suspected, most doctors recommend that the woman be examined by a gynecologic oncologist (a doctor who specializes in diagnosing and treating female reproductive system cancers).

### **Complete 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. You will be given a general physical and a pelvic exam.

## **Sampling and testing endometrial tissue**

To find the cause of abnormal uterine bleeding, a sample of tissue will be removed from the lining of the uterus and looked at under a microscope. The tissue can be sampled by endometrial biopsy or by dilation and curettage (D&C). Often a hysteroscopy is done with the D&C.

These procedures let the doctor see if the bleeding is caused by benign endometrial overgrowth (hyperplasia), endometrial carcinoma, uterine sarcoma, or some other disease. The tests will find many endometrial stromal sarcomas, but less than half of leiomyosarcomas (LMSs). These tests don't find all LMSs because these cancers begin in the middle layer of the wall of the uterus. In order to be found by an endometrial biopsy or D&C, they need to have spread from the middle (muscle) layer to the inner lining of the uterus. Often it is only possible to diagnose a LMS by surgically removing it.

### **Endometrial biopsy**

In this procedure, a very thin, flexible tube is inserted into the uterus through the cervix. Then, using suction, a small amount of endometrium is removed through the tube. Suctioning takes about a minute or less. The discomfort is similar to severe menstrual cramps and can be helped by taking a nonsteroidal anti-inflammatory drug such as ibuprofen an hour before starting. This procedure is usually done in the doctor's office.

### **Hysteroscopy**

This is a procedure that allows doctors to look inside the uterus. A tiny telescope is inserted into the uterus through the cervix. To get a better view, the uterus is then expanded by filling it with salt water (saline). This lets the doctor see and biopsy anything abnormal, such as a

cancer or a polyp. This procedure is usually done with the patient awake, using local anesthesia (numbing medicine). But if a polyp or mass has to be removed, general anesthesia is needed.

### **Dilation and curettage**

If the results of the endometrial biopsy are not conclusive (meaning they can't tell for sure if cancer is present), a procedure called dilation and curettage (D&C) must be done. A D&C does not require admission to the hospital -- it is usually done in the outpatient surgery area of a clinic or hospital. This procedure is done while the woman is under general anesthesia or conscious sedation (medicine is given into a vein to make her drowsy) and takes about an hour. In a D&C, the cervix is dilated and a special surgical instrument is used to scrape tissue from inside the uterus. A hysteroscopy may be done as well. Most women have little discomfort after this procedure.

### **Testing endometrial tissue**

Any tissue samples obtained by these procedures are looked at under the microscope to see if cancer is present. If cancer is found, the lab report will say if it is a carcinoma or sarcoma, what type it is, and what grade it is. A tumor's grade is based on how much it looks like normal tissue under the microscope. If the tumor looks a lot like normal tissue, it is called low grade. If it doesn't at all look like normal tissue, it is high grade. The rate at which the cancer cells appear to be growing is another important factor in grading a uterine sarcoma. High-grade sarcomas tend to grow and spread more quickly than low-grade sarcomas.

The tissue may also be tested to see if the cancer cells contain *estrogen receptors* and *progesterone receptors*. These hormone receptors are found on some endometrial stromal sarcomas. Cancers with these receptors on the cells are more likely to grow in response to the hormones estrogen and progesterone. These cancers may stop growing (or even shrink) when these hormones are blocked with certain drugs. Checking for these receptors helps predict which patients will benefit from treatment with hormone blocking drugs.

### **Cystoscopy and proctoscopy**

If a woman has signs or symptoms that suggest the uterine sarcoma has spread to the bladder or rectum, the inside of these organs can be looked at through a lighted tube. These examinations are called cystoscopy and proctoscopy, respectively, but are rarely done in the diagnosis and work-up of patients with uterine sarcoma.

## **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 inserted into the vagina. The sound waves are used to create images of the uterus and other pelvic organs. These images can often show any tumor that is present and whether or not it affects the myometrium (muscular layer of the uterus).

For an ultrahysterosonogram or saline infusion sonogram, salt water (saline) is placed into the uterus through a small tube before the transvaginal sonogram. This allows the doctor to see abnormalities of the uterine lining more clearly.

### **Computed tomography**

The computed tomography scan (CT scan or CAT scan) is an x-ray procedure that produces detailed cross-sectional images of your body. For a CT scan, you lie on a table while x-rays are taken. Instead of taking one picture, like a regular x-ray, a CT scanner takes many pictures as the camera rotates around you. A computer then combines these pictures into an image of a slice of your body. The machine will take pictures of many slices of the part of your body that is being studied.

Before any pictures are taken, 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 (intravenous) line through which a different kind of contrast dye (IV contrast) is injected. This helps better outline structures in your body.

The injection can cause some flushing (redness and warm feeling that may last hours to days). A few people are allergic to the dye and get hives. Rarely, more serious reactions like trouble breathing and low blood pressure can occur. Medicine can be given to prevent and treat allergic reactions. Be sure to tell the doctor if you have ever had a reaction to any contrast material used for x-rays.

CT scans are rarely used to diagnose uterine cancer, but they may be helpful in seeing if the cancer has spread to other organs.

CT scans can also be used to guide a biopsy needle precisely into a suspected area of cancer spread. For this procedure, called a *CT-guided needle biopsy*, the patient remains on the CT scanning table, while a radiologist moves a biopsy needle toward the location of the mass. CT scans are repeated until the doctors are confident that the needle is within the mass. A fine needle biopsy sample (tiny fragment of tissue) or a core needle biopsy sample (a thin cylinder of tissue about one-half inch long and less than one-eighth inch in diameter) is removed and examined under a microscope.

CT scans take longer than regular x-rays and you need to lie still on a table in a ring while they are being done. But just like other computerized devices, they are getting faster and your stay might be pleasantly short. Also, you might feel a bit confined staying still in the ring while the pictures are being taken.

## **Magnetic resonance imaging**

Magnetic resonance imaging (MRI) scans use radio waves and strong magnets instead of x-rays. The energy from the radio waves is absorbed and then released in a pattern formed by the type of tissue and by certain diseases. A computer translates the pattern of radio waves given off by the tissues into a very detailed image of parts of the body. Not only does this produce cross-sectional slices of the body like a CT scanner, it can also produce slices that are parallel with the length of your body. A contrast material might be injected just as with CT scans but is used less often. MRI scans can help tell if a uterine tumor looks like cancer, but a biopsy is still needed to tell for sure. MRI scans are particularly helpful in looking for cancer that has spread to the brain and spinal cord.

MRI scans take longer than CT scans -- often up to an hour. You are placed inside a tube, which is confining and can upset people with claustrophobia. The machine also makes clicking or buzzing noises that some people may find disturbing. Most places provide headphones and music to block this sound.

## **Positron emission tomography scan**

In the positron emission tomography (PET) scan, radioactive glucose (sugar) is injected into the patient's vein to look for cancer cells. Because cancers use glucose at a higher rate than normal tissues, the radioactivity will tend to concentrate in the cancer. A scanner can spot the radioactive deposits. This test can be helpful for spotting small collections of cancer cells. It may also help tell if a tumor is benign or malignant. PET scans are not yet routinely used for patients with a pelvic mass or abnormal bleeding.

## **Chest x-ray**

A regular (plain) x-ray of the chest may be done to see if a uterine sarcoma has metastasized (spread) to the lungs and as part of the testing before surgery

## **How is uterine sarcoma staged?**

*Staging* is the process of analyzing information about a tumor to find out how far the cancer has spread. The stage of a uterine sarcoma is the most important factor in choosing treatment. Ask your health care team to explain your cancer's stage so that you can make fully informed choices about your treatment.

The system used to stage endometrial cancer is called the FIGO (International Federation of Gynecology and Obstetrics) system of staging. This is a surgical staging system. This means that staging is based on examination of tissue removed during an operation. The FIGO system classifies the cancer in stages I through IV, with each of these stages being further

divided by letters (for example, stages IIA, IIB, and IIC). The FIGO staging system that is used for uterine sarcomas is the same as the one used to stage endometrial carcinomas.

The staging system looks at how far the cancer has spread. It can spread *locally* to other parts of the uterus. It can also spread *regionally* to nearby lymph nodes (bean-sized organs that are part of the immune system). The regional lymph nodes are found in the pelvis and farther away along the aorta (the main artery that runs from the heart down along the back of the abdomen and pelvis). The lymph nodes along the aorta are called para-aortic nodes. Finally, the cancer can spread (*metastasize*) to distant lymph nodes or organs such as lung, liver, bone, brain, and others.

**Stage I:** The cancer is only in the main body of the uterus. It has not spread to the cervix, lymph nodes, or distant sites.

**Stage IA:** The cancer is only in the lining of the uterus (the endometrium).

**Stage IB:** The cancer has spread from the endometrium into the myometrium (muscular wall of the uterus), growing less than halfway through the myometrium.

**Stage IC:** The cancer has spread from the endometrium into the myometrium, growing more than halfway through the myometrium. The cancer has not spread beyond the body of the uterus.

**Stage II:** The cancer has spread from the body of the uterus to the cervix (the lower part of the uterus next to the vagina). The cancer has not spread to lymph nodes or distant sites.

**Stage IIA:** The cancer involves the body of the uterus and the lining of the cervix.

**Stage IIB:** The cancer is in the body of the uterus and has grown through the lining of the cervix and into the supporting connective tissue (called the cervical stroma).

**Stage III:** The cancer has spread outside the uterus but is still only in the pelvic area.

**Stage IIIA:** The cancer has not spread to lymph nodes or distant sites, but it has spread to:

- the layer of tissue on the outer surface of the uterus (the serosa)
- the fallopian tubes or ovaries (adnexa)
- the peritoneal fluid (fluid from the inner lining of the pelvis and abdomen).

**Stage IIIB:** The cancer has spread beyond the uterus to the vagina. It has not spread to lymph nodes or distant sites.

**Stage IIIC:** The cancer has spread to lymph nodes near the uterus (pelvic and/or para-aortic lymph nodes).

**Stage IV:** The cancer has spread to the inner surface of the urinary bladder or the rectum (lower part of the large intestine), to lymph nodes in the groin, and/or to distant organs, such as the bones or lungs.

**Stage IVA:** The cancer has spread to the inner lining of the rectum or urinary bladder (called the mucosa). It may also be in the lymph nodes but has not spread to distant sites.

**Stage IVB:** The cancer has spread to organs that are not next to the uterus (such as the bones or lungs) or it has spread to distant lymph nodes (such as those in the groin area).

## Survival rates by stage

The 5-year survival rate refers to the percentage of patients who live *at least 5 years* after their cancer is diagnosed. Five-year rates are used to produce a standard way of discussing prognosis. Of course, many people live much longer than 5 years. Five-year *relative* survival rates compare the survival of people with the cancer to the survival for people without the cancer. Since some people will die of causes other than cancer, this is a way to look only at deaths from the specific cancer. The 5-year relative survival rate is a more accurate way to describe the outlook for patients with a particular type and stage of cancer. Remember that these numbers are based on patients diagnosed at least 5 years ago. Improvements in treatment since that time may have improved survival for women diagnosed more recently.

The outlook for survival (prognosis) for women with a uterine sarcoma depends on many factors. These include

- The stage of the cancer
- The type of sarcoma (leiomyosarcoma or endometrial stromal sarcoma)
- The grade of the sarcoma (low grade versus high grade)
- The patient's general state of health

The survival statistics noted below are estimates based on studies of women with uterine sarcomas. Although they reflect the average outlook for groups of patients, it is important to always remember that people are not statistics. Every person is different, and every person will have his/her own experience with cancer and its treatment.

The 5-year relative survival rates for **leiomyosarcoma** are:

Stage I: 60%  
Stage II: 35%  
Stage III: 28%  
Stage IV: 15%

The 5-year relative survival rates for **endometrial stromal sarcoma** are:

Stage I: 90%

Stage II: 40% (note: there were only a small number in this group, so may not be accurate)

Stage III: 64%

Stage IV: 37%

## How is uterine sarcoma 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.*

## Considering treatment options

After the diagnostic tests are done, your cancer care team will recommend one or more treatment options. Don't feel rushed about making a decision. If there is anything you do not understand, ask to have it explained again. The choice of treatment depends largely on the type of cancer and stage of the disease when it is diagnosed. Other factors might play a part in choosing the best treatment plan. These might include your age, your overall state of health, whether you plan to have children, and other personal considerations. Be sure you understand all of the risks and side effects of different treatment options before making a decision.

From the start, keep in mind that you will be dealing with your own body and emotions. In the process of deciding what kind of treatment to have, you will find it helpful to discuss options with your family and friends, as well as with your primary care doctor and nurse. At every step of the way, before treatment, during treatment, and in recovery, you should talk with your cancer care team about side effects and ways to avoid them or make them easier to endure. They want to answer your questions, so ask them!

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 certain treatments, but a second opinion is usually not required for routine cancer treatments.

There are 4 basic types of treatment for women with uterine sarcoma:

- Surgery
- Radiation therapy
- Chemotherapy
- Hormone therapy

A combination of these treatments may be used. Which treatment(s) is used depends on the type and stage of your cancer as well as your overall medical condition. Most women with uterine sarcoma have surgery to remove the cancer. Radiation, chemo, and hormonal therapy are sometimes given to lower the risk of the cancer coming back after surgery. These treatments may also be used for cancers that cannot be removed with surgery or when a woman can't have surgery because she has other health problems.

## **Surgery**

Surgery is the primary (main) treatment for uterine sarcoma. The major goal of surgery is to remove all of the cancer. This usually means removing the uterus, but for some tumors, the fallopian tubes, ovaries, and part of the vagina may also need to be removed. Some lymph nodes or other tissue may be taken out as well to see if the cancer has spread outside the uterus. Which procedures are done depend on the type and grade of the cancer and how far it has spread. The patient's general health and age are also important factors. In some cases, tests done before surgery allow the doctor to plan the operation in detail ahead of time. These tests include imaging studies, such as CT scans and ultrasound, as well as the pelvic examination, endometrial biopsy, and/or D&C. In other cases, the surgeon has to decide which options to take based on what is found during surgery. For example, sometimes there is no way to know for certain that a tumor is cancer until it is removed during surgery.

## **Hysterectomy**

This surgery removes the whole uterus (the body of the uterus and the cervix). This procedure is sometimes called a simple hysterectomy or a total hysterectomy. In a simple hysterectomy, the loose connective tissue around the uterus (parametrium), the tissue connecting the uterus and sacrum (uterosacral ligaments), and the vagina remain intact. Removing the ovaries and fallopian tubes is not actually part of a hysterectomy -- it is a separate procedure known as a bilateral salpingo-oophorectomy (BSO). The BSO is often done along with a hysterectomy in the same operation (see below).

If the uterus is removed through a surgical incision in the front of the abdomen, it is called an abdominal hysterectomy. When the uterus is removed through the vagina, it is called a vaginal hysterectomy. If lymph node sampling is needed, this can be done through the same

incision as the abdominal hysterectomy. If a hysterectomy is done through the vagina, lymph nodes can be removed using a laparoscope. A laparoscope is sometimes used to help remove the uterus when the doctor is doing a vaginal hysterectomy. This is called a *laparoscopic assisted vaginal hysterectomy*. The uterus can also be removed through the abdomen with a laparoscope. This procedure requires less recovery time than a regular abdominal hysterectomy.

Either general or regional anesthesia is used for the procedure -- this means that the patient is asleep or sedated. For an abdominal hysterectomy the hospital stay is usually 3 to 5 days. Complete recovery takes about 4 to 6 weeks. A laparoscopic procedure and vaginal hysterectomy usually require a hospital stay of 1 to 2 days and a 2- to 3-week recovery. After a hysterectomy, a woman cannot become pregnant and give birth to children. Surgical complications are unusual but could include excessive bleeding, wound infection, or damage to the urinary or intestinal systems.

### **Radical hysterectomy**

This operation removes the entire uterus as well as the tissues next to the uterus (parametrium and uterosacral ligaments) and the upper part (about 1 inch) of the vagina (near the cervix). This operation is used more often for cervical carcinomas than for uterine sarcomas.

This operation is most often done through an abdominal surgical incision, although it can also be performed through the vagina. Most patients undergoing a radical hysterectomy also have a lymph node dissection, in which lymph nodes are removed either through the abdominal incision or by laparoscopic lymph node sampling. Radical hysterectomy can be done using either general or regional anesthesia.

Because more tissue is removed by a radical hysterectomy than with a simple hysterectomy, the hospital stay may be longer -- about 5 to 7 days. The surgery leaves the woman unable to become pregnant and give birth to children. Complications are unusual but could include excessive bleeding, wound infection, and damage to the urinary or intestinal systems.

### **Bilateral salpingo-oophorectomy**

This operation removes both fallopian tubes and both ovaries. In treating endometrial carcinomas and uterine sarcomas, this operation is usually done at the same time the uterus is removed (either by simple hysterectomy or radical hysterectomy). If both of your ovaries are removed, you will go into menopause if you have not done so already.

Symptoms of menopause include hot flashes, night sweats, and vaginal dryness. These symptoms are caused by a lack of estrogen and may be improved with estrogen therapy (ET). This therapy also lowers a woman's risk of osteoporosis (weakening and thinning of the bones). However, since estrogen can cause some types of uterine cancer to grow, many doctors are concerned that it could increase the chance of the cancer coming back. Most

experts in this field consider ET too risky for most women who have had uterine sarcoma. Some doctors prescribe it only when the stage and grade of the cancer indicate a very low risk of the cancer coming back. A woman who has had uterine sarcoma should discuss the risks and benefits of ET with her doctor before making a decision. There are other treatments for symptoms of menopause and prevention of osteoporosis.

### **Lymph node surgery**

Your surgeon may do a procedure called a lymph node dissection, which removes the lymph nodes in the pelvis and around the aorta (the main artery that runs from the heart down along the back of the abdomen and pelvis). These lymph nodes are examined under a microscope to see if they contain cancer cells. If cancer is found in the lymph nodes, it means that the cancer has already spread outside of the uterus. This carries a poor prognosis (outlook for survival). This operation is done through the same surgical incision in the abdomen as the simple abdominal hysterectomy or radical abdominal hysterectomy. If a vaginal hysterectomy has been done, the lymph nodes can be removed with laparoscopic surgery.

### **Other procedures that may be done during surgery**

- **Omentectomy:** The omentum is a layer of fatty tissue that covers the abdominal contents like an apron. Cancer sometimes spreads to this tissue. When this tissue is removed, it is called an *omentectomy*. The omentum is sometimes removed during a hysterectomy if cancer has spread there or as a part of staging.
- **Peritoneal biopsies:** The tissue lining the pelvis and abdomen is called the *peritoneum*. Peritoneal biopsies remove small pieces of this lining to check for cancer cells.
- **Pelvic washings:** In this procedure, the surgeon "washes" the abdominal and pelvic cavities with salt water (saline) and sends the fluid to the lab to see if it contains cancer cells.
- **Tumor debulking:** If cancer has spread throughout the abdomen, the surgeon may attempt to remove as much of the tumor as possible. This is called *debulking*. For some types of cancer, debulking can help other treatments, like radiation or chemotherapy, work better. Its role in treating uterine sarcoma is not clear.

### **Sexual impact of surgery**

For women who are premenopausal, removing the uterus causes menstrual bleeding (periods) to stop. If the ovaries were also removed, menopause will occur. This can lead to vaginal dryness and pain during intercourse. These symptoms can be improved with estrogen treatment, but this hormone may need to be avoided for women with certain tumors. Other medicines may be helpful in those cases.

While physical and emotional changes can affect the desire for sex, these surgeries do not prevent a woman from feeling sexual pleasure. A woman does not need ovaries or a uterus to have sex or reach orgasm. Surgery can actually improve a woman's sex life, if the cancer caused problems with pain or bleeding during sex.

For more information on this topic, see our document *Sexuality for the Woman With Cancer*.

## **Radiation therapy**

Radiation therapy uses high-energy radiation (such as x-rays) to kill cancer cells. These treatments may be given externally in a procedure that is much like having a diagnostic x-ray. This is called *external beam* radiation therapy.

Radiation therapy also may be given by placing radioactive materials near the tumor. This is called *brachytherapy*. Women treated with this type of radiation do not remain radioactive after the implant is removed. In some situations, both brachytherapy and external beam radiation therapy are given.

When the tumor can be seen growing through the cervix, radiation therapy can make it easier to completely remove the cancer with surgery. Radiation may also be given after surgery to lower the chance of the cancer coming back in the pelvis. This, known as *adjuvant radiation*, may be done for cancers that are high grade or when cancer cells are found in the lymph nodes. In those cases, the entire pelvis may be treated with external beam radiation therapy about 4 to 6 weeks after surgery. Sometimes the radiation field will also include an area of the abdomen called the para-aortic field. This is the area in the abdomen around the aorta (the main artery).

Radiation may be done instead of surgery in a woman who can't have surgery because of other health problems.

### **External beam radiation therapy**

External beam radiation therapy is the more familiar type of treatment in which the radiation is delivered from an outside source. This therapy requires treatment 5 days a week for 4 or 5 weeks. The skin covering the area that is exposed to radiation is carefully marked with permanent ink or injected dye, similar to a tattoo. A special mold of the pelvis and lower back is custom-made to ensure that the woman is placed in the exact same position for each treatment. The actual external beam radiation treatment takes less than 30 minutes.

### **Brachytherapy**

Brachytherapy places radioactive materials close to the area to be treated (such as the tumor).

How much of the pelvis needs to be exposed to radiation therapy depends on the extent of the disease. In cases where only the upper third of the vagina (the vaginal cuff) needs to be treated, radioactive material is inserted through the vagina. This is called *vaginal brachytherapy*.

For this treatment, a cylinder with a source of radiation is inserted into the vagina. With this method, the radiation mainly affects the area in contact with the cylinder, such as the vaginal cuff (the upper third of the vagina). Nearby structures such as the bladder and rectum get little radiation exposure.

This procedure is done in the radiation suite of the hospital or care center. About 4 to 6 weeks after the hysterectomy, the surgeon or radiation oncologist inserts a special applicator into the woman's vagina, and pellets of radioactive material are inserted into the applicator. There are 2 types of brachytherapy: low-dose rate (LDR) and high-dose rate (HDR).

In LDR brachytherapy, the pellets are usually left in place for about a day at a time. The patient needs to stay immobile to keep the pellets from moving during treatment, and so she is usually kept in the hospital overnight. Several treatments may be necessary.

In HDR brachytherapy, the radiation is more intense. Each dose takes a very short period of time (usually less than an hour), and the patient can return home the same day. For uterine cancers, HDR brachytherapy is often given weekly or even daily for at least 3 doses.

### **Side effects of radiation therapy**

Common side effects of radiation therapy include tiredness, upset stomach, or loose bowels. Serious fatigue, which may not occur until a few weeks after treatment begins, is a common side effect.

Skin changes are also common, with the skin in the treated area looking and feeling sunburned. As the radiation passes through the skin to its intended target, it may damage the skin cells. This can cause irritation that ranges from temporary and mild redness to permanent discoloration. The skin may release fluid, which can lead to infection, so care must be taken to clean and protect the area exposed to radiation.

Diarrhea is a common side effect, but it can usually be controlled with over-the-counter medicines. Nausea and vomiting may also occur, but can be treated with medicines. Side effects tend to be worse when chemotherapy is given with radiation.

Radiation can irritate the bladder and may cause problems with urination. Bladder irritation, called *radiation cystitis*, can cause discomfort and an urge to urinate frequently.

Radiation therapy may also cause scar tissue to form in the vagina. If the scar tissue makes the vagina shorter or more narrow it is called *vaginal stenosis*. This can make vaginal intercourse painful. A woman can help prevent this problem by stretching the walls of her

vagina several times a week. This can be done by having sexual intercourse 3 to 4 times a week or by using a vaginal dilator (a plastic or rubber tube used to stretch out the vagina). Still, vaginal dryness and pain with intercourse can be long-term side effects from radiation. Pelvic radiation can damage the ovaries, resulting in premature menopause. This isn't an issue for most women being treated for uterine sarcoma because they have already gone through menopause, either naturally or as a result of surgery to treat the cancer.

As long as a woman is not bleeding heavily from a tumor in her bladder, rectum, uterus, cervix, or vagina, she can still continue to have sex during the course of pelvic radiation therapy. However, the outer genitals and vagina may become sore and tender to touch, and many women choose to stop having intercourse for a while, to let the area heal.

Radiation can also lead to low blood counts, causing anemia (low red blood cells) and leukopenia (low white blood cells). The blood counts usually return to normal after radiation is stopped.

Radiation to the pelvis can impair fluid drainage from the legs, leading to leg swelling. This is known as *lymphedema* and is more common in women who had lymph nodes removed during surgery.

Pelvic radiation also can weaken the bones, leading to fractures of the hips or pelvic bones. It is important that women who have had pelvic radiation contact their doctor right away if they have pelvic pain. Such pain might be caused by a fracture, recurrent cancer, or other serious conditions.

If you are having any side effects from radiation, discuss them with your cancer care team. There are things you can do to get relief from these symptoms or prevent them.

## Chemotherapy

Chemotherapy (chemo) is the use of drugs to treat cancer. The drugs can be swallowed in pill form, or they can be injected by needle into a vein or muscle. Chemotherapy is considered systemic therapy. This means that the drug enters the bloodstream and circulates throughout the body to reach and destroy cancer cells - making this treatment useful for cancer that has spread beyond the uterus. When chemotherapy is given to shrink the cancer before surgery, it is called *neoadjuvant* treatment. If it is given after the cancer has been completely removed with surgery it is called *adjuvant* therapy. Adjuvant treatments are meant to keep the cancer from coming back later. Chemo can also be used as the main therapy to treat the cancer.

Chemotherapy often means treatment with a combination of drugs. Some of the drugs used to treat uterine sarcomas include: doxorubicin (Adriamycin<sup>®</sup> or Doxil<sup>®</sup>), ifosfamide, cisplatin, paclitaxel (Taxol<sup>®</sup>), gemcitabine (Gemzar<sup>®</sup>) and docetaxel (Taxotere<sup>®</sup>). There are many new promising agents being studied in uterine sarcoma. Which drugs are used depends on the type of uterine sarcoma and any prior health problems.

These drugs kill cancer cells but can also damage some normal cells. This is what causes many side effects. Side effects of chemotherapy depend on the specific drugs, the amount taken, and the length of time you are treated. Some common side effects include:

- Nausea and vomiting
- Loss of appetite
- Hair loss
- Low blood counts

Chemotherapy can damage the blood-producing cells of the bone marrow, leading to low blood cell counts. This can result in:

- An increased chance of serious infection (due to a shortage of white blood cells)
- Problems with bleeding or bruising (due to a shortage of blood platelets)
- Feeling tired or short of breath (due to low red blood cell counts)

It is important to let your cancer care team know about any problems you have while on chemo, because many side effects can be prevented or treated. For example, there are many good medicines to prevent or reduce nausea and vomiting. Most side effects of chemotherapy stop when the treatment is over.

However, some side effects from chemotherapy can last a long time. For example, the drug doxorubicin can damage the heart muscle over time. The chance of heart damage goes up as the total dose of the drug goes up, so doctors place a limit on how much doxorubicin is given. Cisplatin can cause kidney damage. Giving large amounts of fluid before and after chemotherapy can help protect the kidneys. Both cisplatin and paclitaxel can cause nerve damage (called *neuropathy*). This can lead to numbness, tingling, or even pain in the hands and feet.

## Hormone therapy

Hormone therapy is the use of hormones or hormone-blocking drugs to fight cancer. It is mainly used to treat patients with endometrial stromal sarcomas and is rarely used for the other type of uterine sarcoma.

### Progestins

Progesterone-like hormones such as megestrol (Megace<sup>®</sup>) or medroxyprogesterone (Provera<sup>®</sup>) can be used. Side effects can include increased blood sugar levels in patients with diabetes. Hot flashes, night sweats, and weight gain (from fluid retention and an increased appetite) also occur. Rarely, serious blood clots are seen in patients taking progestins.

### Gonadotropin-releasing hormone agonists

Gonadotropin-releasing hormone (GNRH) agonists switch off estrogen production by the ovaries. These drugs are useful in lowering estrogen levels in women who are premenopausal. Examples of GNRH agonists include goserelin (Zoladex<sup>®</sup>) and leuprolide (Lupron<sup>®</sup>). These drugs are injected every 1 to 3 months. Side effects can include any of the symptoms of menopause, such as hot flashes and vaginal dryness. If they are taken for a long time (years), these drugs can weaken bones (sometimes leading to osteoporosis).

### **Aromatase inhibitors**

After the ovaries are removed (or are not functioning), estrogen is still made in fat tissue. This becomes the body's main source of estrogen. Drugs called aromatase inhibitors can stop this estrogen from being formed. Examples of aromatase inhibitors include letrozole (Femara<sup>®</sup>), anastrozole (Arimidex<sup>®</sup>), and exemestane (Aromasin<sup>®</sup>). These drugs are most often used to treat breast cancer, but may be helpful in the treatment of endometrial stromal sarcoma. Side effects can include hot flashes and joint/muscle pain. If they are taken for a long time (years), these drugs can weaken bones (sometimes leading to osteoporosis).

### **Tamoxifen**

Tamoxifen is an anti-estrogen drug that is often used to treat breast cancer. It can also be used to treat endometrial stromal sarcoma. The goal of tamoxifen therapy is to prevent any estrogens circulating in the woman's body from stimulating growth of the cancer cells. Even though tamoxifen may prevent estrogen from nourishing the cancer cells, it acts like a weak estrogen in other areas of the body. It does not cause bone loss, but can cause hot flashes and vaginal dryness. People taking tamoxifen also have an increased risk of serious blood clots in the legs.

## **Clinical trials**

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 Web site at <http://clinicaltrials.cancer.org>. 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 Web site at [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials).

There are requirements you must meet to take part in any clinical trial. If you do qualify for a clinical trial, however, you decide whether or not to enter (enroll in) it.

Clinical trials are one way to get state-of-the-art cancer treatment. They are 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*. You can read it on our Web site or call our toll-free number and have it sent to you.

## **Complementary and alternative therapies**

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 Web sites 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 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 in general and to find out about the specific methods you are looking at.

### **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 by stage**

Surgery to remove the uterus, fallopian tubes, and ovaries and sample the lymph nodes is the main treatment for uterine sarcomas. Sometimes this is followed by treatment with radiation, chemotherapy, or hormone therapy. Treatments given after the cancer has been completely removed with surgery are called adjuvant treatments. Adjuvant therapy is given to help keep the cancer from coming back. This approach has helped patients with certain cancers, like colon and breast cancer, live longer. So far, though, adjuvant treatments for uterine sarcoma have not helped patients live longer. Since both types of uterine sarcoma are rare, it has been hard to study them well.

Women who can't have surgery because they have other health problems are may be treated with radiation, chemotherapy, or hormone therapy. Often some combination of these other treatments is used.

### **Stages I and II**

**Leiomyosarcoma and undifferentiated sarcoma:** Most women have surgery to remove the uterus, fallopian tubes and ovaries (hysterectomy and bilateral salpingo-oophorectomy). Pelvic and para-aortic lymph node dissection or laparoscopic lymph node sampling is

recommended for most patients. During surgery, organs near the uterus and the peritoneum (the thin membrane that lines the pelvic and abdominal cavities) are carefully examined to determine if the cancer has spread beyond the uterus.

In young women with low-grade leiomyosarcomas (LMS) that have not spread beyond the uterus, the surgeon may rarely be able to leave the uterus, fallopian tubes, and ovaries in place, and instead remove only the tumor along with a rim of the normal tissue around it. This approach is not standard treatment, so it is not often offered. It may rarely be a choice for some women who want to still be able to have children after their cancer has been treated. This option has risks, however, so women considering this surgery need to discuss the possible risks and benefits with their gynecologic oncologist before making a decision. Close follow-up is important, and additional surgery may be needed if the cancer comes back.

After surgery, treatment with radiation (sometimes with chemo) may be recommended. This treatment may lower the chance that the cancer will come back in the pelvis. The goal of surgery is to remove all of the cancer, but the surgeon can only remove what can be seen. Tiny clumps of cancer cells that are too small to be seen can be left behind. Treatments given after surgery are meant to kill those cancer cells so that they don't get the chance to grow into larger tumors. When chemotherapy or radiation is used after surgery like this, it is called *adjuvant therapy*.

For LMS of the uterus, most studies have found that adjuvant radiation can reduce the risk of local recurrence, but it doesn't seem to help women live longer. Since the cancer can still come back in the lungs or other distant organs, some experts recommend using adjuvant chemotherapy. So far, results from studies of adjuvant chemotherapy have been promising in early stage LMS, but long-term follow-up is still needed to see if survival is really improved. Studies of adjuvant therapy are still in progress. For anyone being treated for uterine LMS, entering a clinical trial is always a good option.

**Endometrial stromal sarcoma:** Early stage endometrial stromal sarcoma is treated with surgery-- hysterectomy, bilateral salpingo-oophorectomy, and lymph node removal. After surgery, most patients do not need further treatment. These women are watched closely for signs that the cancer has returned. Some doctors give radiation to the pelvis, hormone therapy, or both to lower the chances of the cancer coming back, but this has not been shown to improve survival.

Patients who are too sick (from other medical conditions) to have surgery may be treated with radiation and/or hormone therapy.

### **Stage III**

For either type of uterine sarcoma, surgery is done to remove all of the cancer. This includes a hysterectomy, bilateral salpingo-oophorectomy, and lymph node dissection. If the tumor has spread to the vagina (stage IIIB), part (or even all) of the vagina will need to be removed as well. Treatment after surgery depends on the type of sarcoma.

Adjuvant treatment with radiation (with or without chemo) may be offered for leiomyosarcomas.

Women with endometrial stromal sarcomas might receive radiation, hormonal treatment, or both after surgery.

Patients who are too sick (from other medical conditions) to have surgery may be treated with radiation, chemo, and/or hormone therapy.

## **Stage IV**

There is currently no standard treatment for these cancers. If the cancer can be completely removed with surgery, this is usually done. If the cancer cannot be removed completely, radiation may be given, either alone or with chemotherapy. Women with stage IV uterine sarcomas might consider taking part in clinical trials (scientific studies of promising treatments) testing new chemotherapy or other treatments. Preliminary studies have found that chemotherapy drugs can shrink some uterine sarcomas but usually cannot cure these cancers. For endometrial stromal sarcomas, hormone therapy and/or radiation may be helpful.

## **Recurrent uterine sarcoma**

If a cancer comes back after treatment, it is called recurrent. If the cancer comes back in the same area as it was in the first place, it is called a local recurrence. For uterine sarcoma, the cancer growing back as a tumor in the pelvis would be a local recurrence. If it comes back in another area like the liver or lungs, it is called a distant recurrence.

Unfortunately, uterine sarcoma often comes back in the first few years after treatment. Treatment options are the same as those for stage IV. If the cancer can be removed, surgery may be done. Radiation may be used to reduce the size of the tumor and relieve the symptoms of large pelvic tumors. Sarcoma often comes back as spread to the lungs. If there are only 1 or 2 small tumors, these may be able to be removed with surgery. Some patients have been cured by this treatment.

## **More treatment information**

For more details on treatment and the side effects of treatment -- including some that may not be addressed in this document -- the National Comprehensive Cancer Network (NCCN) and the National Cancer Institute (NCI) are good sources of information.

The NCCN, made up of experts from many of the nation's leading cancer centers, develops cancer treatment guidelines for doctors to use when treating patients. Those are available on the NCCN Web site ([www.nccn.org](http://www.nccn.org)).

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

## What should you ask your doctor about uterine sarcoma?

It is important for you to have honest, open discussions with your cancer care team. The following are some questions to consider:

- What type and grade of uterine sarcoma do I have?
- Has the cancer spread beyond the uterus?
- What is the stage of my cancer and what does that mean in my case?
- 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?
- What are the chances of recurrence of my cancer with the treatment options we have discussed?
- Should I follow a special diet?
- Will I be able to have children after my treatment?
- What is my expected prognosis, based on what you know about my cancer?
- When will I be able to return to daily activities?
- How will this affect my sex life?
- Does this cancer prevent me from considering estrogen replacement therapy?

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

## What will happen after treatment for uterine sarcoma?

Completing treatment can be both stressful and exciting. You will be relieved to finish treatment, yet it is hard not to worry about cancer coming back (when cancer returns, it is called recurrence). This is a very common concern among those who have had cancer.

It may take a while before your confidence in your own recovery begins to feel real and your fears are somewhat relieved. You can learn more about what to look for and how to learn to live with the possibility of cancer coming back in our document, *Living With Uncertainty: The Fear of Cancer Recurrence*, available at 1-800-227-2345.

## Follow-up care

After your treatment is over, it is very important to keep all follow-up appointments. During these visits, your doctors will ask about symptoms, do physical exams, and order blood tests or imaging studies such as CT scans or x-rays. Follow-up is needed to check for cancer recurrence or spread, as well as possible side effects of certain treatments. This is the time for you to ask your health care team any questions you need answered and to discuss any concerns you might have.

Almost any cancer treatment can have side effects. Some may last for a few weeks to several months, but others can be permanent. Don't hesitate to tell your cancer care team about any symptoms or side effects that bother you so they can help you manage them.

It is also important to keep medical insurance. Even though no one wants to think of their cancer coming back, it is always a possibility. If it happens, the last thing you want is to have to worry about paying for treatment. Should your cancer come back our document, *When Your Cancer Comes Back: Cancer Recurrence* gives you information on how to manage and cope with this phase of your treatment. You can get this document by calling 1-800-227-2345.

## Seeing a new doctor

At some point after your cancer diagnosis and treatment, you may find yourself in the office of a new doctor. Your original doctor may have moved or retired, or you may have moved or changed doctors for some reason. It is important that you be able to give your new doctor the exact details of your diagnosis and treatment. Make sure you have the following information handy:

- A copy of your pathology report from any biopsy or surgery
- If you had surgery, a copy of your operative report
- If you had radiation, a copy of your treatment summary
- If you were hospitalized, a copy of the discharge summary that every doctor must prepare when patients are sent home from the hospital
- Finally, since some drugs can have long-term side effects, a list of your chemotherapy and hormone therapy drugs, drug doses, and when you took them

## Lifestyle changes to consider during and after treatment

Having cancer and dealing with treatment can be time-consuming and emotionally draining, but it can also 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 begin this process during cancer treatment.

### **Make healthier choices**

Think about your life before you learned you had cancer. Were there things you did that might have made you less healthy? Maybe you drank too much alcohol, or ate more than you needed, or smoked, or didn't exercise very often. Emotionally, maybe you kept your feelings bottled up, or maybe you let stressful situations go on too long.

Now is not the time to feel guilty or to blame yourself. However, you can start making changes today that can have positive effects for the rest of your life. Not only will you feel better but you will also be healthier. What better time than now to take advantage of the motivation you have as a result of going through a life-changing experience like having cancer?

You can start by working on those things that you feel most concerned about. 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's Quitline<sup>®</sup> tobacco cessation program at 1-800-227-2345.

### **Diet and nutrition**

Eating right can be a challenge for anyone, but it can get even tougher during and after cancer treatment. For instance, treatment often may change your sense of taste. Nausea can be a problem. You may lose your appetite for a while and lose weight when you don't want to. On the other hand, some people gain weight even without eating more. This can be frustrating, too.

If you are losing weight or have taste problems during treatment, do the best you can with eating and remember that these problems usually improve over time. You may want to ask your cancer team for a referral to a dietitian, an expert in nutrition who can give you ideas on how to fight some of the side effects of your treatment. You may also find it helps to eat small portions every 2 to 3 hours until you feel better and can go back to a more normal schedule.

One of the best things you can do after treatment is to put healthy eating habits into place. You will be surprised at the long-term benefits of some simple changes, like increasing the variety of healthy foods you eat. Try to eat 5 or more servings of vegetables and fruits each day. Choose whole grain foods instead of white flour and sugars. Try to limit meats that are high in fat. Cut back on processed meats like hot dogs, bologna, and bacon. Get rid of them altogether if you can. If you drink alcohol, limit yourself to 1 or 2 drinks a day at the most. And don't forget to get some type of regular exercise. The combination of a good diet and regular exercise will help you maintain a healthy weight and keep you feeling more energetic.

## **Rest, fatigue, work, and exercise**

Fatigue is a very common symptom in people being treated for cancer. This is often not an ordinary type of tiredness but a "bone-weary" exhaustion that doesn't get better with rest. For some, this fatigue lasts a long time after treatment, and can discourage them from physical activity.

However, exercise can actually help you reduce fatigue. Studies have shown that patients who follow an exercise program tailored to their personal needs feel physically and emotionally improved and can cope better.

If you are ill and need to be on bed rest during treatment, it is normal to expect your fitness, endurance, and muscle strength to decline some. Physical therapy can help you maintain strength and range of motion in your muscles, which can help fight fatigue and the sense of depression that sometimes comes with feeling so tired.

Any program of 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 3 times a week. If you haven't exercised in a few years but can still get around, you may want to think about taking short walks.

Talk with your health care team before starting, and get their opinion about your exercise plans. Then, try to get an exercise buddy so that 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, though, you will need to balance activity with rest. It is okay to rest when you need to. It is really hard for some people to allow themselves to do that when they are used to working all day or taking care of a household. (For more information about fatigue, please see our document, *Fatigue in People With Cancer*.)

Exercise can improve your physical and emotional health.

- It improves your cardiovascular (heart and circulation) fitness.
- It strengthens your muscles.
- It reduces fatigue.
- It lowers anxiety and depression.
- It makes you feel generally happier.
- It helps you feel better about yourself.

And long term, we know that exercise plays a role in preventing some cancers. The American Cancer Society, in its guidelines on physical activity for cancer prevention, recommends that adults be physically active for 30 minutes or more on 5 days or more of the

week. Children and teens are encouraged to try for at least 60 minutes a day of energetic physical activity on at least 5 days a week.

## **How about your emotional health?**

Once your treatment ends, you may find yourself overwhelmed by 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 it.

Now you may find that you think about the possibility of your own death, or the effect of your cancer on your family, friends, and career. You may also begin to re-evaluate your relationship with your spouse or partner. Unexpected issues may also cause concern -- for instance, as you become healthier and have fewer doctor visits, you will see your health care team less often. That can be a source of anxiety for some.

This is an ideal time to seek out emotional and social 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 individual counselors.

Almost everyone who has been through cancer can benefit from getting some type of support. 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 realistic to go it all by yourself. And your friends and family may feel shut out if you decide not to 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 an appropriate group or resource.

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 healthy choices and feeling as well as possible, physically and emotionally.

## **What happens if treatment is no longer working?**

If cancer continues to grow after one kind of treatment, or if it returns, it is often possible to try another treatment plan that might still cure the cancer, or at least shrink the tumors enough to help you live longer and feel better. On the other hand, when a person has received several different medical treatments and the cancer has not been cured, over time the cancer tends to become resistant to all treatment. At this time it's important to weigh the possible

limited benefit of a new treatment against the possible downsides, including continued doctor visits and treatment side effects.

Everyone has his or her own way of looking at this. Some people may want to focus on remaining comfortable during their limited time left.

This is likely to be the most difficult time in your battle with cancer -- when you have tried everything medically within reason and it's just not working anymore. Although your doctor may offer you new treatment, you need to consider that at some point, continuing treatment is not likely to improve your health or change your prognosis or survival.

If you want to continue treatment to fight your cancer as long as you can, you still need to consider the odds of more treatment having any benefit. In many cases, your doctor can estimate the response rate for the treatment you are considering. Some people are tempted to try more chemotherapy or radiation, for example, even when their doctors say that the odds of benefit are less than 1%. In this situation, you need to think about and understand your reasons for choosing this plan.

No matter what you decide to do, it is important that you be as comfortable as possible. Make sure you are asking for and getting treatment for any symptoms you might have, such as pain. This type of treatment is called palliative treatment.

Palliative treatment helps relieve these symptoms, but is not expected to cure the disease; its main purpose is to improve your quality of life. Sometimes, the treatments you get to control your symptoms are similar to the treatments used to treat cancer. For example, radiation therapy might be given to help relieve bone pain from bone metastasis. Or chemotherapy might be given to help shrink a tumor and keep it from causing a bowel obstruction. But this is not the same as receiving treatment to try to cure the cancer.

At some point, you may benefit from hospice care. Most of the time, this is given at home. Your cancer may be causing symptoms or problems that need attention, and hospice focuses on your comfort. You should know that receiving hospice care doesn't mean you can't have treatment for the problems caused by your cancer or other health conditions. It just means that the focus of your care is on living life as fully as possible and feeling as well as you can at this difficult stage of your cancer.

Remember also that maintaining hope is important. 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. In a way, pausing at this time in your cancer treatment is an opportunity to refocus on the most important things in your life. This 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.

## **What's new in uterine sarcoma research and treatment?**

## **Molecular pathology of uterine sarcoma**

Recent research has improved our understanding of how changes in certain molecules can cause normal cells to become cancerous. For several years we have known that mutations (damage or defects) to DNA can alter important genes that regulate cell growth. If these genes are damaged, excess growth may result in cancer formation. Analysis of DNA from uterine sarcomas has revealed several changes in the genes that control cell growth. Each human cell contains 23 pairs of chromosomes. In most endometrial stromal sarcomas (especially low grade ones), there is an abnormal “swapping” of chromosomal material (DNA) between chromosomes 7 and 17. Part of chromosome 7 goes to 17 and part of 17 goes to 7. This is known as a *translocation*. The swapping of DNA between the chromosomes leads to the formation of a new gene, called *JAZF1/JJAZ1*, which causes the cells to become malignant.

Scientists expect that these discoveries such as this will eventually lead to new strategies for detection, prevention, and treatment.

## **Clinical trials**

New drugs, as well as new ways to give standard drugs are being tested. One drug under study, trabectedin (Yondelis<sup>®</sup>) has had some promising results in early trials of patients with sarcoma. Another drug, temozolomide, which is approved to treat brain tumors, also seems to help patients with sarcoma. Adjuvant radiation and chemotherapy continue to be evaluated for treatment of uterine sarcomas. New compounds are also being evaluated in soft-tissue sarcomas. Some of these compounds act differently from traditional chemotherapy drugs and are called targeted therapies.

## **Additional resources**

### **More information from your American Cancer Society**

The following information may also be helpful to you. These materials may be ordered from our toll-free number, 1-800-227-2345:

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

Anemia in People With Cancer

Clinical Trials: What You Need to Know

Endometrial (Uterine) Cancer (also available in Spanish)

Fatigue in People With Cancer

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

Understanding Chemotherapy (also available in Spanish)

Understanding Radiation Therapy (also available in Spanish)

The following books are available from the American Cancer Society. Call us at 1-800-227-2345 to ask about costs or to place your order.

*American Cancer Society's Guide to Pain Control: Understanding and Managing Cancer Pain, Revised Edition*

*Caregiving: A Step-By-Step Resource for Caring for the Person With Cancer at Home, Revised Edition*

*When the Focus Is on Care: Palliative Care and Cancer*

## **National organizations and Web sites\***

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

### **Gynecologic Cancer Foundation**

Toll-free number: 1-800-444-4441

Web site: [www.thegcf.org](http://www.thegcf.org)

### **National Cancer Institute**

Toll-free number: 1-800-4-CANCER (1-800- 422-6237) or TTY 1-800-332-8615

Web site: [www.cancer.gov](http://www.cancer.gov)

*\*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 [www.cancer.org](http://www.cancer.org).

## **References**

Amant F, Coosemans A, Renard V, Everaert E, Vergote I. Clinical outcome of ET-743 (Trabectedin; Yondelis) in high-grade uterine sarcomas: report on five patients and a review of the literature. *Int J Gynecol Cancer*. 2009;19:245-248.

American Cancer Society. *Cancer Facts and Figures 2009*. Atlanta, Ga: American Cancer Society; 2009.

Bodurka DC, Gershenson DM. Sarcomas of the female reproductive tract. In: Pollock RE, ed. *American Cancer Society Atlas of Clinical Oncology*. Soft Tissue Sarcomas. Hamilton, Ontario: BC Decker; 2002:213-227.

Chan JK, Kawar NM, Shin JY, et al. Endometrial stromal sarcoma: a population-based analysis. *Br J Cancer*. 2008;99:1210-1215.

Chu CS, Lin LL, Rubin SC. Cancers of the uterine body. In: DeVita VT, Hellman S, Rosenberg SA, eds. *Cancer: Principles and Practice of Oncology*. 8th ed. Philadelphia, Pa: Lippincott Williams & Wilkins 2008: 1543-1563.

Fields A, Jones JG, Thomas GM, Runowicz CD. Gynecologic cancer. In: Lenhard RE Jr, Osteen RT, Gansler T, eds. *Clinical Oncology*. Atlanta, Ga: American Cancer Society; 2001:455-496.

Hensley ML, Ishill N, Soslow R, et al. Adjuvant gemcitabine plus docetaxel for completely resected stages I-IV high grade uterine leiomyosarcoma: Results of a prospective study. *Gynecol Oncol*. 2009;112:563-567.

Horner MJ, Ries LAG, Krapcho M, et al (eds). SEER Cancer Statistics Review, 1975-2006, National Cancer Institute. Bethesda, MD, [http://seer.cancer.gov/csr/1975\\_2006/](http://seer.cancer.gov/csr/1975_2006/), based on November 2008 SEER data submission, posted to the SEER web site, 2009.

Hrzenjak A, Moinfar F, Tavassoli FA, et al. JAZF1/JJAZ1 gene fusion in endometrial stromal sarcomas: molecular analysis by reverse transcriptase-polymerase chain reaction optimized for paraffin-embedded tissue. *J Mol Diagn*. 2005;7:388-395.

Kosary CL. Cancer of the Corpus Uteri. In: Ries LAG, Young JL, Keel GE, Eisner MP, Lin YD, Horner M-J (editors). SEER Survival Monograph: Cancer Survival Among Adults: U.S. SEER Program, 1988-2001, Patient and Tumor Characteristics. National Cancer Institute, SEER Program, NIH Pub. No. 07-6215, Bethesda, MD, 2007.

National Comprehensive Cancer Network. Uterine Neoplasms. V.2.2009. Accessed at [www.nccn.org](http://www.nccn.org) on September, 2009.

PDQ database. Uterine sarcoma. Bethesda, Md: National Cancer Institute; 5/22/2008. Accessed at [www.cancer.gov](http://www.cancer.gov) on September, 2009.

Rahaman J, Cohen CJ. Gynecologic sarcomas. In: Kufe DW, Pollock RE, Weichselbaum RR, Bast RC, Gansler TS, Holland JF, Frei E, eds. *Cancer Medicine 6*. Hamilton, Ontario: BC Decker; 2003:1871-1878.

Last Medical Review: 11/18/2009

Last Revised: 11/18/2009

2009 Copyright American Cancer Society

For additional assistance please contact your American Cancer Society  
1 · 800 · ACS-2345 or [www.cancer.org](http://www.cancer.org)