



## UTERINE SARCOMA

### What is cancer?

Cancer develops when cells in a part of the body begin to grow out of control. Although there are many kinds of cancer, they all start because of out-of-control growth of abnormal cells.

Normal body cells grow, divide, and die in an orderly fashion. During the early years of a person's life, normal cells divide more rapidly until the person becomes an adult. After that, cells in most parts of the body divide only to replace worn-out or dying cells and to repair injuries.

Because cancer cells continue to grow and divide, they are different from normal cells. Instead of dying, they outlive normal cells and continue to form new abnormal cells.

Cancer cells develop because of damage to DNA. This substance is in every cell and directs all its activities. Most of the time when DNA becomes damaged the body is able to repair it. In cancer cells, the damaged DNA is not repaired. People can inherit damaged DNA, which accounts for inherited cancers. Many times though, a person's DNA becomes damaged by exposure to something in the environment, like smoking.

Cancer usually forms as a tumor. Some cancers, like leukemia, do not form tumors. Instead, these cancer cells involve the blood and blood-forming organs and circulate through other tissues where they grow.

Often, cancer cells travel to other parts of the body, where they begin to grow and replace normal tissue. This process is called metastasis. Regardless of where a cancer may spread, however, it is always named for the place it began. For instance, breast cancer that spreads to the liver is still called breast cancer, not liver cancer.

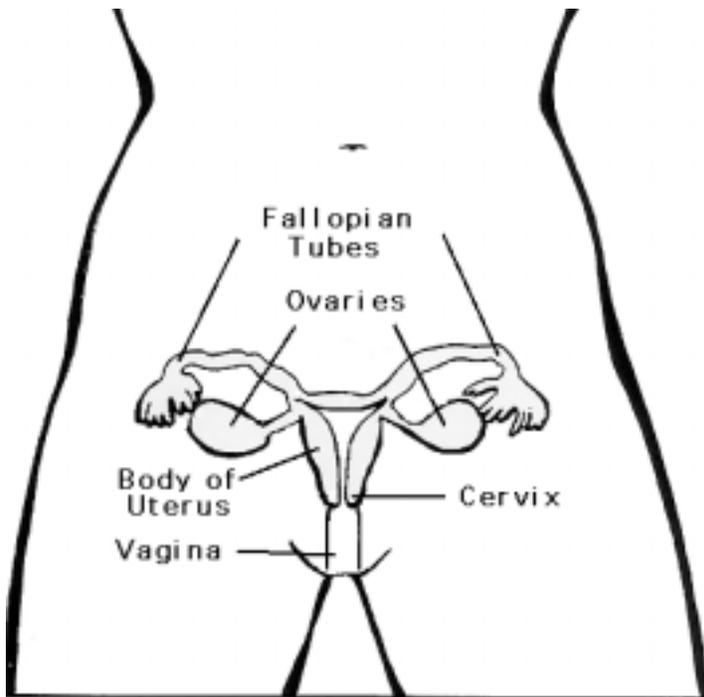
Not all tumors are cancerous. Benign (non-cancerous) tumors do not spread (metastasize) to other parts of the body and, with very rare exceptions, are not life threatening.

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.

Cancer is the second leading cause of death in the United States. Nearly half of all men and a little over one third of all women in the United States will develop cancer during their lifetimes. Today, millions of people are living with cancer or have had cancer. The risk of developing most types of cancer can be reduced by changes in a person's lifestyle, for example, by quitting smoking and eating a better diet. The sooner a cancer is found and treatment begins, the better are the chances for living for many years.

## What Is Uterine Sarcoma?

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



*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 the cells, called epithelial cells, that line or cover most organs are called *carcinomas*.

More than 95% of cancers of the uterus are carcinomas, cancers that develop from epithelial cells of the lining layers of that organ. Carcinomas of the lower part of the uterus above the vagina, called the cervix, are called *cervical carcinomas*. Carcinomas that develop from the lining cells of the upper part of the uterus, called the body or corpus of the uterus, are called

*endometrial carcinomas*. These cancers are discussed in separate documents available from the American Cancer Society. This document is about *uterine sarcomas*.

Most uterine sarcomas fall into 1 of 3 categories, based on the type of cell they developed from:

- **Endometrial stromal sarcomas** develop in the *stroma* (supporting connective tissue) of the endometrium.
- **Uterine leiomyosarcomas** start in the muscular wall of the uterus.
- **Uterine carcinosarcomas**, once known as malignant mixed mesodermal tumors or malignant mixed mullerian tumors (MMMT), start in the endometrium and have features of both sarcomas and carcinomas. They are usually classified with uterine sarcomas, but some doctors believe they are more closely related to carcinomas.

Among this group of uterine cancers, carcinosarcomas are the most common, followed by leiomyosarcomas. Endometrial stromal sarcomas are the least common.

Several types of benign (non-cancerous) tumors, such as leiomyomas, adenofibromas, and adenomyomas, can also develop in the connective tissues of the uterus. These are also called benign uterine fibroid tumors. If they cause symptoms such as pressure or excessive bleeding, these tumors are usually treated by surgical removal of the uterus (hysterectomy). In some cases, the tumor can be removed without removing the entire uterus, depending on the woman's age and reproductive wishes. The remainder of this document refers to uterine sarcomas.

## What Are the Key Statistics About Uterine Sarcoma?

An estimated 40,100 new cases of cancer of the uterine corpus (body of the uterus) will be diagnosed in the United States during 2008, but more than 95% of these will be endometrial cancers. Incidence rates of uterine sarcoma cancer have been decreasing by about 1% per year since 1998 after a period of increase during the previous decade. An estimated 7,470 women in the United States will die from cancer of the uterine corpus during 2008. Death rates from uterine sarcoma have been stable since 1992 after decreasing an average of 1.5% per year from 1975-1992.

According to estimates from various studies, uterine sarcomas (including carcinosarcomas, leiomyosarcomas, and endometrial stromal sarcomas) account for around 4% of cancers of the uterus. That means that about 1,600 cases are expected in 2008.

## What Are the Risk Factors for Uterine Sarcoma?

A risk factor is anything that increases 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 cancers of the lung, mouth, larynx, bladder, kidney, and several other organs. But having a risk factor, or even several, does not mean that a person will get the disease.

Several factors can increase the risk of developing a uterine sarcoma.

## **Prior Pelvic Radiation Therapy**

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

## **Race**

Uterine sarcomas are about twice as common in African Americans as in whites or Asians. The reason for this increased risk is unknown.

## **Endometrial Cancer Risk Factors**

Factors that increase a woman's risk of developing endometrial cancer also increase her risk for developing carcinosarcoma, but not any of the other types of uterine sarcoma. The following factors tend to be related to levels of the female hormones, estrogen and progesterone, and all increase the amount of estrogen and how long a woman's uterus is exposed to it, or change the balance between estrogen and progesterone toward more estrogen:

- obesity
- certain types of estrogen replacement therapy
- treatment with tamoxifen (a hormonal drug used for breast cancer treatment and breast cancer risk reduction)
- infertility
- diabetes
- menstrual periods before age 12
- menopause after age 52

Remember, however, that these factors increase the risk for developing some uterine sarcomas, but they do not always cause the disease. Most women with one or more of these risk factors never have a uterine sarcoma, and other women who have uterine sarcomas do not have any known risk factors.

## **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 therapy in treating other cancers far outweighs the risk of developing a rare cancer such as uterine sarcoma many

years later. Likewise, the benefit of taking tamoxifen for a woman with breast cancer far outweighs her risk of developing uterine sarcoma.

## 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 may reach an advanced stage before recognizable signs and symptoms are present. These signs and symptoms differ among the 3 main types of uterine sarcoma.

### Screening Tests

At this time, no recommended screening tests or examinations are available that can detect most uterine sarcomas in women without symptoms (asymptomatic). The Pap test can occasionally find some early uterine sarcomas (especially carcinosarcomas and endometrial stromal sarcomas), but most cases (especially leiomyosarcomas) are not detected by this test.

In contrast, the Pap test is very effective in finding early carcinomas of the cervix (the lower part of the uterus). Please refer to the ACS document on Cervical Cancer for information on screening tests for cervix cancer.

Women who have had a total hysterectomy (removal of the uterus and cervix) may also choose to stop having cervical cancer screening, unless the surgery were done as treatment for cervical cancer or precancer. Women who have had a hysterectomy without removal of the cervix should continue to follow the American Cancer Society guidelines for screening for cervical cancer.

## How Is Uterine Sarcoma Diagnosed?

In most cases, the possibility of uterine sarcoma is suggested by certain symptoms. These symptoms do not specifically indicate that a woman has a uterine sarcoma. In fact, they are more often caused by non-cancerous changes in the uterus, by pre-cancerous overgrowth of the endometrium, or by an endometrial carcinoma. Doctors use one or more tests to distinguish among these possibilities. Most carcinosarcomas and endometrial stromal sarcomas are diagnosed during evaluation of these symptoms.

### Signs and Symptoms of Uterine Sarcomas

**Bleeding or spotting:** If you have gone through menopause, it is especially important to report bleeding or spotting to your health care professional. About 85% of patients diagnosed with uterine sarcoma have symptoms of postmenopausal bleeding or spotting (bleeding between periods). Although this can occur with benign (non-cancerous) conditions such as hormonal imbalances and rarely with some infections, it is important to have an immediate medical evaluation of bleeding after menopause or unusual bleeding before menopause. Abnormal bleeding is more likely to be caused by carcinosarcomas or endometrial stromal sarcomas than by leiomyosarcomas.

**Other discharge:** About 10% of women with uterine sarcomas have a discharge without any visible blood. Although such discharges are usually a sign of some benign condition such as infection, absence of visible blood in a discharge does not mean cancer is absent. Any abnormal discharge should be investigated by your health care professional.

**Pelvic pain and/or mass:** About 10% of women have pain and/or a mass that can be felt at the time their uterine sarcoma is diagnosed. In other cases, you or your doctor can feel a mass in your uterus, or you have a feeling of "fullness" in your pelvis.

## Consultation, Medical History, and Physical Exam

**Consult with a specialist:** If a uterine tumor 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:** At the first step in the consultation, your doctor will gather information about your personal and family medical history. You will be asked about symptoms, risk factors, and any other health problems.

**Complete physical exam:** This will include a general physical and a pelvic exam.

## Sampling and Testing Endometrial Tissue

If you have abnormal uterine bleeding, a sample of tissue from the lining of your uterus must be removed and examined under the microscope to find out if it is benign endometrial overgrowth (hyperplasia), endometrial carcinoma, uterine sarcoma, or some other disease. The tissue can be sampled by endometrial biopsy or by dilation and curettage (D & C) with or without a hysteroscopy (a test in which a gynecologist looks at the inside of the uterus through a thin, lighted tube).

These procedures will find nearly all carcinosarcomas and many endometrial stromal sarcomas. Less than half of leiomyosarcomas will be found in this way, because these cancers begin in the wall of the uterus and often have not spread to the lining of the uterine cavity -- the area sampled by an endometrial biopsy or D & C.

**Endometrial biopsy:** A sample of endometrial tissue is obtained through a very thin, flexible tube inserted into the uterus through the cervix. The doctor removes a small amount of endometrium through the tube by using suction. The suctioning takes about a minute or less. The discomfort is similar to severe menstrual cramps and can be minimized by taking a nonsteroidal anti-inflammatory drug such as ibuprofen an hour before the procedure. This is usually done in the doctor's office.

**Hysteroscopy:** This is a procedure that allows doctors to look inside the uterus. Doctors insert a tiny telescope into the uterus through the cervix. The uterus is then expanded by filling with saline. This lets the doctor see the abnormality that might be causing the bleeding, such as a cancer or a polyp, and then that abnormality can be biopsied. This is usually done with local anesthesia.

**Dilation and curettage (D&C):** If the endometrial biopsy does not provide enough tissue or suggests but does not diagnose cancer, a D&C with or without a hysteroscopy must be done. In this outpatient procedure, the cervix is dilated and a special surgical instrument is used to scrape tissue from inside the uterus.

The procedure takes about an hour and may require general anesthesia or conscious sedation (medication is given into a vein to make you drowsy but able to stay awake). A D&C is usually done in an outpatient surgery area of a clinic or hospital. Most women have little discomfort after this procedure.

**Testing of endometrial tissue:** Tissue samples removed by endometrial biopsy, D&C, or hysteroscopic resection are examined under the microscope to determine if cancer is present. If these tests find cancer, it will be identified as a specific type of carcinoma or sarcoma and will be graded. The tumor's grade is based on whether its appearance under the microscope looks like normal tissue (very closely -- low grade or only remotely -- 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 endometrial biopsy, D&C specimen, or tissue removed during hysteroscopy can also be used to test if the cancer cells contain *estrogen receptors* and *progesterone receptors*. The ovaries produce the hormones progesterone and estrogen to help regulate the growth of normal cells of the uterus. As noted in the section "What Are the Risk Factors for Uterine Sarcoma?", having too much estrogen in relation to progesterone increases a woman's risk of developing endometrial carcinoma and some types of uterine sarcoma.

For normal cells to respond to these hormones, they must contain special proteins that recognize estrogen and progesterone. These recognition proteins are called receptors and can be identified by lab tests. Some endometrial stromal sarcomas that contain estrogen and progesterone receptors depend on these hormones to grow. Hormonal therapies that prevent estrogen production or block the action of this hormone can slow the growth of some endometrial stromal sarcomas.

**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.

## Imaging Tests

**Transvaginal ultrasound:** A transvaginal sonogram (ultrasound) uses sound waves to create images of the uterus. A probe inserted into the vagina releases sound waves that echo off the tissues of the pelvic organs. A computer analyzes the pattern of echoes to create images on a computer screen. These images often help determine whether a tumor is present and whether it affects the myometrium (muscular wall of the uterus).

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

**Computed tomography (CT):** The CT scan is an x-ray procedure that produces detailed cross-sectional images of your body. Instead of taking one picture, as does a conventional x-ray, a CT scanner takes many pictures as it rotates around you. A computer then combines these pictures into an image of a slice of your body. The machine will take pictures of many slices of the part of your body that is being studied.

This test can help tell if your cancer has spread into other organs. Often after the first set of pictures is taken you will receive an intravenous (IV) injection of a radiocontrast agent, or "dye," that helps better outline structures in your body. A second set of pictures is then taken.

CT scans can also be used to precisely guide a biopsy needle into a suspected metastasis. 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 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 by the ring you lie within when the pictures are being taken.

The injection can also cause some flushing. Some people are allergic and get hives, or rarely, more serious reactions like trouble breathing and low blood pressure can occur. Be sure to tell the doctor if you have ever had a reaction to any contrast material used for x-rays. You may be asked to drink 1 to 2 pints of a solution of contrast material. This helps outline the intestine.

**Magnetic resonance imaging (MRI):** 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 may help tell if a uterine tumor is benign or malignant. MRI scans are particularly helpful in looking for cancer 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. Some places provide headphones with music to block this sound.

**Positron emission tomography (PET) scan:** In this test, radioactive glucose (sugar) is injected into the patient's vein. Because cancers use sugar much faster than normal tissues, the cancerous tissue takes up the radioactive material. A scanner can spot the radioactive deposits. This test, which is still being studied, may be useful for telling whether a uterine tumor is benign or malignant. However, it is not yet routinely used for patients with a pelvic mass or abnormal bleeding.

**Chest x-rays:** These images are routinely taken to see if a uterine sarcoma has metastasized (spread) to the lungs.

## 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 the stage of your cancer 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 endometrial cancer staging system is also used for uterine sarcomas.

**Stage I:** The cancer is only in the main body of the uterus.

**Stage IA:** The tumor is only in the lining of the uterus.

**Stage IB:** The tumor has invaded into the body of the uterus but not more than halfway.

**Stage 1C:** The tumor has invaded more than halfway into 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).

**Stage IIA:** The cancer has spread only into the lining of the cervix.

**Stage IIB:** The cancer is invading through the lining of the cervix.

**Stage III:** The cancer has spread beyond or outside the uterus but remains only in the pelvic area.

**Stage IIIA:** The cancer has spread to the layer of tissue on the outer surface of the uterus (the serosa) or to the tissues immediately to the right and left sides of the uterus (adnexa), or microscopic examination found cancer cells in *peritoneal fluid* (fluid from the inner lining of the pelvis and abdomen).

**Stage IIIB:** The cancer has spread beyond the uterus to the vagina.

**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 (mucosa) of the urinary bladder or the *rectum* (lower part of the large intestine), and/or has spread to lymph nodes in the groin, and/or has spread to organs that are not next to the uterus, such as the bones or lungs.

**Stage IVA:** The cancer has spread to the inner surface (mucosa) of the rectum or urinary bladder.

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

## 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 exclude patients dying of other diseases. This means that anyone who died of another cause, such as heart disease, is not counted.

The outlook for chances of survival (prognosis) for women with a uterine sarcoma depends on many factors. The stage of the cancer is one important factor, but the type of sarcoma (carcinosarcoma, leiomyosarcoma, or endometrial stromal sarcoma), the grade of the sarcoma (low grade versus high grade), and your general state of health also affect your prognosis.

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, they cannot reliably predict the outlook for any particular individual. Also, the survival statistics are 5-year survival rates, meaning that they are based on follow-up of women diagnosed more than 5 years ago. Advances in treatment may make the outlook more favorable for women diagnosed more recently.

The 5-year survival is around 50% for women with stage I and II uterine sarcoma, around 20% for those with stage III sarcomas, and 10% or less for those with stage IV sarcomas. These numbers are very approximate because they come from small numbers of patients treated at single hospitals many years ago.

## 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.

The 4 basic types of treatment for women with uterine sarcoma are surgery, radiation therapy, chemotherapy, and hormone therapy. A combination of these treatments may be used. The choice of treatment(s) will depend on the type and stage of your cancer and your overall medical condition.

### Surgery

The choice of surgical procedures to treat uterine sarcoma is mainly based on the stage, type, and grade of the cancer. This decision is also based on a woman's general state of health and her age. In some cases, a firm surgical plan is based on pre-operative (before surgery) tests, such as imaging studies and results of the pelvic examination, endometrial biopsy, and/or D&C. In other cases, the surgeon begins the operation with several options that were selected

based on the pre-operative examination and test results. A decision about which of these options to take depends on what the surgeon finds during the surgery.

### **Simple Hysterectomy**

This is surgical removal of the whole uterus (the body of the uterus and the cervix). The loose connective tissue around the uterus (parametrium) and the tissue connecting the uterus and sacrum (uterosacral ligaments) are not removed, and the vagina remains intact.

The operation is called an abdominal hysterectomy if it involves a surgical incision in the front of the abdomen. 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.

General anesthesia or regional anesthesia is used so that the patient is asleep or sedated during the procedure. 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.

Most gynecological cancer surgeons prefer, and experts recommend, the abdominal operation along with a bilateral salpingo-oophorectomy (see below) if they suspect cancer. This gives them a better opportunity to see if the cancer has spread as compared to a vaginal hysterectomy.

### **Radical Hysterectomy**

Like a hysterectomy, this operation removes the entire uterus. However, the tissues next to the uterus (parametrium and uterosacral ligaments) and the upper part (about 1 inch) of the vagina next to the cervix are also removed. This operation is used when endometrial carcinoma has spread to the cervix or parametrium but is rarely performed for sarcomas.

As in a simple abdominal hysterectomy, general or regional anesthesia and an abdominal surgical incision are used, although a radical hysterectomy can also be performed through the vagina. Most patients undergoing a radical hysterectomy also have a lymph node sampling procedure, which can be done through the abdominal incision or by laparoscopic lymph node sampling.

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.

**Sexual impact of hysterectomy:** Following hysterectomy, no menstrual bleeding will take place because the uterus has been removed. Hysterectomy does not prevent a woman from feeling sexual pleasure. A woman does not need a uterus or cervix to reach orgasm.

Even though there are no changes in a woman's physical functioning, she may feel less feminine after a hysterectomy. Some women may view themselves as "an empty shell." On the other hand, when cancer has caused pain or bleeding with intercourse, the hysterectomy may improve a woman's sex life by stopping those symptoms.

### **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). Removal of both ovaries means that you will go into menopause if you have not done so already.

Many symptoms associated with menopause (such as hot flashes, night sweats, vaginal dryness) can be relieved by estrogen therapy (ET). This therapy also lowers a woman's risk of osteoporosis (weakening and thinning of the bones). However, use of ET is controversial in women with some types of uterine cancer because of the potential of increasing the risk of recurrent disease or the slight chance of increasing the risk of other hormonally related cancers, such as breast cancer.

Therefore, women who have had uterine sarcoma and who are making decisions about ET must balance the risks (recurrent or other hormonally related cancers) and benefits (relief of symptoms and protection against some other diseases, such as osteoporosis). Most experts in this field would either avoid prescribing ET for women who have had uterine sarcoma or prescribe it only when the stage and grade of the cancer indicate a very low risk of recurrence. There are other treatments for symptoms of menopause and prevention of osteoporosis. Ask your doctor about these options.

### **Lymph Node Surgery**

Your surgeon may remove the lymph nodes that are in the pelvis and lower abdomen in the back (called para-aortic nodes). This operation determines whether the uterine sarcoma has spread to these nodes. If there is cancer found in the lymph nodes, the cancer has already spread beyond the uterus which carries a poor prognosis. This operation is done through the same surgical incision in the abdomen as the simple abdominal hysterectomy or radical abdominal hysterectomy or with laparoscopic surgery if a vaginal hysterectomy has been done. Although this may make the recovery period a bit longer, there should be no lasting side effects from this part of the operation.

### **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. The radiation delivered from a machine outside the body does not cause the body to become radioactive. 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.

### **External Beam Radiation Therapy**

Pre-operative external and internal radiation therapy may be used if the cervix is grossly involved by tumor. If the cancer is high grade (indicating a potential for lymph node involvement) or if microscopic examination of lymph nodes found cancer cells, the entire pelvis may be treated with external beam radiation therapy after surgery. Depending on the location of affected lymph nodes, the radiation field may be extended to also include an area of the abdomen called the para-aortic field.

External beam radiation therapy is the more familiar type 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**

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

This is done in some women instead of surgery if they can't withstand surgery or in those that have had surgery, 4 to 6 weeks after the hysterectomy. The surgeon or radiation oncologist inserts a special applicator into the woman's vagina and then inserts pellets of radioactive material into the applicator. This is done in the radiation suite of the hospital or care center. Several treatments may be necessary. With vaginal brachytherapy, the radiation has little effect on nearby structures such as the bladder or rectum. In some situations, both brachytherapy and external beam radiation therapy are given.

### **Side Effects of Radiation Therapy**

Fatigue, which may not occur until several weeks after therapy begins, is a common side effect.

As the radiation passes through the skin to its intended target, it may damage the skin cells, causing 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 non-prescription medications. Bladder irritation, called radiation cystitis, may also occur, resulting in discomfort and an urge to urinate frequently. Pelvic radiation therapy may cause vaginal

stenosis (narrowing of the vagina by scar tissue), which might make intercourse painful. But intercourse or inserting a dilator into the vagina can help prevent vaginal stenosis. The use of local estrogens may help in dryness and atrophy.

As long as a woman is not bleeding heavily from a tumor in her bladder, rectum, uterus, cervix, or vagina, she can usually have intercourse during the course of pelvic radiation therapy. However, touching the outer genitals and vagina may become uncomfortable, and most women refrain from intercourse during and for several weeks following radiation therapy.

Premature menopause may also occur as a side effect of radiation therapy. However, most women who have radiation therapy for uterine sarcoma also have had both ovaries removed. If a woman is not already menopausal, this surgery would cause premature menopause. Premature menopause is not usually a concern since most women diagnosed with uterine sarcoma are past 50.

If you are having any side effects from radiation, discuss them with your cancer care team. There are things you can do to obtain relief from these symptoms or prevent their occurrence, such as using vaginal dilators to manage vaginal stenosis.

## Chemotherapy

Chemotherapy uses drugs that are most commonly given through a vein or by mouth. These drugs enter the bloodstream and reach all areas of the body, making this treatment useful for cancer that has spread beyond the uterus. If this treatment is chosen, you may receive a combination of drugs. Drugs used in treating uterine sarcomas may include doxorubicin, ifosfamide, cisplatin, paclitaxel, and gemcitabine. The choice of chemotherapy drugs is influenced by the woman's type of uterine sarcoma.

These drugs kill cancer cells but can also damage some normal cells, which in turn can cause side effects. Therefore, careful attention is given to avoiding or reducing side effects. Side effects of chemotherapy depend on the specific drugs, the amount taken, and the length of time you are treated. They might include nausea and vomiting, loss of appetite, mouth and vaginal sores, and hair loss.

Because chemotherapy can damage the blood-producing cells of the bone marrow, patients may have low blood cell counts. This can result in:

- an increased chance of infection (due to a shortage of white blood cells)
- bleeding or bruising after minor cuts or injuries (due to a shortage of blood platelets)
- fatigue or shortness of breath (due to low red blood cell counts)

Most of these side effects of chemotherapy stop when the treatment is over. If you are taking chemotherapy and have side effects, remember that there are remedies that can prevent or reduce the severity of many of them. For example, anti-nausea medications can prevent or reduce nausea and vomiting. Be sure to talk with your cancer care team about any side effects you are experiencing.

## **Hormone Therapy**

Hormone therapy is mainly used to treat patients with endometrial stromal sarcomas and is rarely used for other types of uterine sarcomas. Progesterone-like hormones such as Megace or Provera can be used. Doctors also use drugs that block a woman's estrogen-producing capacity. If a woman is premenopausal and hasn't had her ovaries removed, then a drug that blocks hormone production by the ovaries is used. These are called gonadotropin-releasing hormone analogues. Most postmenopausal women can use drugs called aromatase inhibitors. These block the small amounts of estrogens produced by tissues other than the ovaries. However, the use of these drugs is considered investigational.

## **Clinical Trials**

You 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 deciding 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 one way to get state-of-the-art cancer care. Still, they are not right for everyone.

Here we will give you a brief review of clinical trials. Talking to your health care team, your family, and your friends can help you make the best treatment choice for you.

### **What Are Clinical Trials?**

Clinical trials are carefully controlled research studies that are done with patients. These studies test whether a new treatment is safe and how well it works in patients, or they may test new ways to diagnose or prevent a disease. Clinical trials have led to many advances in cancer prevention, diagnosis, and treatment.

### **The Purpose of Clinical Trials**

Clinical trials are done to get a closer look at promising new treatments or procedures in patients. A clinical trial is only done when there is good reason to believe that the treatment, test, or procedure being studied may be better than the one used now. Treatments used in clinical trials are often found to have real benefits and may go on to become tomorrow's standard treatment.

Clinical trials can focus on many things, such as:

- new uses of drugs that are already approved by the US Food and Drug Administration (FDA)
- new drugs that have not yet been approved by the FDA
- non-drug treatments (such as radiation therapy)
- medical procedures (such as types of surgery)
- herbs and vitamins
- tools to improve the ways medicines or diagnostic tests are used
- medicines or procedures to relieve symptoms or improve comfort
- combinations of treatments and procedures

Researchers conduct studies of new treatments to try to answer the following questions:

- Is the treatment helpful?
- What's the best way to give it?
- Does it work better than other treatments already available?
- What side effects does the treatment cause?
- Are there more or fewer side effects than the standard treatment used now?
- Do the benefits outweigh the side effects?
- In which patients is the treatment most likely to be helpful?

### **Phases of Clinical Trials**

There are 4 phases of clinical trials, which are numbered I, II, III, and IV. We will use the example of testing a new cancer treatment drug to look at what each phase is like.

**Phase I clinical trials:** The purpose of a phase I study is to find the best way to give a new treatment safely to patients. The cancer care team closely watches patients for any harmful side effects.

For phase I studies, the drug has already been tested in lab and animal studies, but the side effects in patients are not fully known. Doctors start by giving very low doses of the drug to the first patients and increase the doses for later groups of patients until side effects appear or the desired effect is seen. Doctors are hoping to help patients, but the main purpose of a phase I trial is to test the safety of the drug.

Phase I clinical trials are often done in small groups of people with different cancers that have not responded to standard treatment, or that keep coming back (recurring) after treatment. If a drug is found to be reasonably safe in phase I studies, it can be tested in a phase II clinical trial.

**Phase II clinical trials:** These studies are designed to see if the drug works. Patients are given the best dose as determined from phase I studies. They are closely watched for an effect on the cancer. The cancer care team also looks for side effects.

Phase II trials are often done in larger groups of patients with a specific cancer type that has not responded to standard treatment. If a drug is found to be effective in phase II studies, it can be tested in a phase III clinical trial.

**Phase III clinical trials:** Phase III studies involve large numbers of patients -- most often those who have just been diagnosed with a specific type of cancer. Phase III clinical trials may enroll thousands of patients.

Often, these studies are randomized. This means that patients are randomly put in one of two (or more) groups. One group (called the control group) gets the standard, most accepted treatment. Other group(s) get the new one(s) being studied. All patients in phase III studies are closely watched. The study will be stopped early if the side effects of the new treatment are too severe or if one group has much better results than the others.

Phase III clinical trials are usually needed before the FDA will approve a treatment for use by the general public.

**Phase IV clinical trials:** Once a drug has been approved by the FDA and is available for all patients, it is still studied in other clinical trials (sometimes referred to as phase IV studies). This way more can be learned about short-term and long-term side effects and safety as the drug is used in larger numbers of patients with many types of diseases. Doctors can also learn more about how well the drug works, and if it might be helpful when used in other ways (such as in combination with other treatments).

### **What It Will Be Like to Be in a Clinical Trial**

If you are in a clinical trial, you will have a team of experts taking care of you and watching your progress very carefully. Depending on the phase of the clinical trial, you may receive more attention (such as having more doctor visits and lab tests) than you would if you were treated outside of a clinical trial. Clinical trials are specially designed to pay close attention to you.

However, there are some risks. No one involved in the study knows in advance whether the treatment will work or exactly what side effects will occur. That is what the study is designed to find out. While most side effects go away in time, some may be long-lasting or even life threatening. Keep in mind, though, that even standard treatments have side effects. Depending on many factors, you may decide to enter (enroll in) a clinical trial.

### **Deciding to Enter a Clinical Trial**

If you would like to take part in a clinical trial, you should begin by asking your doctor if your clinic or hospital conducts clinical trials. There are requirements you must meet to take part in any clinical trial. But whether or not you enter (enroll in) a clinical trial is completely up to you.

Your doctors and nurses will explain the study to you in detail. They will go over the possible risks and benefits and give you a form to read and sign. The form says that you understand the clinical trial and want to take part in it. This process is known as giving your informed consent. Even after reading and signing the form and after the clinical trial begins, you are free to leave the study at any time, for any reason.

Taking part in a clinical trial does not keep you from getting any other medical care you may need. To find out more about clinical trials, talk to your cancer care team. Here are some questions you might ask:

- Is there a clinical trial that I could take part in?
- What is the purpose of the study?
- What kinds of tests and treatments does the study involve?
- What does this treatment do? Has it been used before?
- Will I know which treatment I receive?
- What is likely to happen in my case with, or without, this new treatment?

- What are my other choices and their pros and cons?
- How could the study affect my daily life?
- What side effects can I expect from the study? Can the side effects be controlled?
- Will I have to stay in the hospital? If so, how often and for how long?
- Will the study cost me anything? Will any of the treatment be free?
- If I am harmed as a result of the research, what treatment would I be entitled to?
- What type of long-term follow-up care is part of the study?
- Has the treatment been used to treat other types of cancers?

### **How Can I Find Out More About Clinical Trials That Might Be Right for Me?**

The American Cancer Society offers a clinical trials matching service for patients, their family, and friends. You can reach this service at 1-800-303-5691 or on our Web site at <http://clinicaltrials.cancer.org>.

Based on the information you give about your cancer type, stage, and previous treatments, this service can put together a list of clinical trials that match your medical needs. The service will also ask where you live and whether you are willing to travel so that it can look for a treatment center that you can get to.

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).

For even more information on clinical trials, the American Cancer Society has a document called *Clinical Trials: What You Need to Know*. You can read this on the Web site, [www.cancer.org](http://www.cancer.org), or have it sent to you by calling 1-800-ACS-2345.

### **Complementary and Alternative Treatments**

When you have cancer you are likely to hear about ways to treat your cancer or relieve symptoms that are different from mainstream (standard) medical treatment. These treatments can include vitamins, herbs, and special diets, or acupuncture and massage—among many others. You may have a lot of questions about these treatments. Here are some you may have thought of already:

- How do I know if the treatment is safe?
- How do I know if it works?
- Should I try one or more of these treatments?
- What does my doctor know/think about these treatments? Should I tell the doctor that I'm thinking about trying them?
- Will these treatments cause a problem with my standard medical treatment?
- What is the difference between "complementary" and "alternative" treatments?
- Where can I find out more about these treatments?

### **The Terms Can Be Confusing**

Not everyone uses these terms the same way, so it can be confusing. The American Cancer Society uses *complementary* to refer to medicines or treatments that are used *along with* your regular medical care. *Alternative* medicine is a treatment used *instead of* standard medical treatment.

**Complementary treatments:** Complementary treatment methods, for the most part, are not presented as cures for cancer. Most often they are used to help you feel better. Some methods that can be used in a complementary way are meditation to reduce stress, acupuncture to relieve pain, or peppermint tea to relieve nausea. There are many others. Some of these methods are known to help and could add to your comfort and well being, while others have not been tested. Some have been proven not to be helpful. A few have even been found harmful.

There are many complementary methods that you can safely use right along with your medical treatment to help relieve symptoms or side effects, to ease pain, and to help you enjoy life more. For example, some people find methods such as aromatherapy, massage therapy, meditation, or yoga to be useful.

**Alternative treatments:** Alternative treatments are those that are used instead of standard medical care. These treatments have not been proven to be safe and effective in clinical trials. Some of these treatments may even be dangerous or have life-threatening side effects. The biggest danger in most cases is that you may lose the chance to benefit from standard treatment. Delays or interruptions in your standard medical treatment may give the cancer more time to grow.

### **Deciding What to Do**

It is easy to see why people with cancer may consider alternative treatments. You want to do all you can to fight the cancer. Sometimes mainstream treatments such as chemotherapy can be hard to take, or they may no longer be working.

Sometimes people suggest that their treatment can cure your cancer without having serious side effects, and it's normal to want to believe them. But the truth is that most non-standard treatments have not been tested and proven to be effective for treating cancer.

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

- Talk to your doctor or nurse about any treatment you are thinking about using.
- Check the list of "red flags" below.
- Contact the American Cancer Society at 1-800-ACS-2345 to learn more about complementary and alternative treatments in general and to learn more about the specific treatments you are thinking about.

### **Red Flags**

You can use the questions below to spot treatments or methods to avoid. A "yes" answer to any one of these questions should raise a "red flag."

- Does the treatment promise a cure for all or most cancers?

- Are you told not to use standard medical treatment?
- Is the treatment or drug a "secret" that only certain people can give?
- Does the treatment require you to travel to another country?
- Do the promoters attack the medical or scientific community?

### **The Decision Is Yours**

Decisions about how to treat or manage your cancer are always yours to make. If you are thinking about using a complementary or alternative method, be sure to learn about it and talk to your doctor about it. With reliable information and the support of your health care team, you may be able to safely use methods that can help you while avoiding those that could be harmful.

### **Treatment Options by Stage**

Surgery, namely hysterectomy and bilateral salpingo-oophorectomy with lymph node sampling is the main treatment for uterine sarcomas. Sometimes this is followed by adjuvant therapy (in addition to the primary treatment which is usually surgery) with radiation or chemotherapy. The role of adjuvant treatment is still debated by the experts. Most studies have found that adjuvant radiation therapy can reduce the risk of cancer coming back locally in the pelvis. And some small studies have found adjuvant chemotherapy or radiation therapy improve disease free survival rates.

**Stages I, II, and III:** The usual treatment is hysterectomy (removal of the body of the uterus and cervix) and salpingo-oophorectomy (removal of the fallopian tubes and ovaries). 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, low-grade leiomyosarcomas that have not spread beyond the uterus can be removed together with a margin of normal tissue, without removing the uterus, fallopian tubes, or ovaries. This approach preserves the patient's fertility and is an option for some women who may wish to have children after their cancer has been treated. However, women considering this option should discuss its advantages and risks with their gynecologic oncologist. Close follow-up is important, and additional surgery will be performed if recurrent cancer is detected.

Even after surgery appears to have removed all of the cancer, local recurrence (cancer coming back in the area of the pelvis) is quite common because many women have cancer cells remaining in the pelvis. These cancer cells are too small to be seen by the surgeon and eventually grow into larger tumors. For this reason, adjuvant radiation therapy (radiation given after apparently complete surgical removal) may be recommended. This treatment can reduce the risk of local recurrence and prevent certain symptoms caused by local recurrence. But, adjuvant radiation therapy does not appear to significantly improve the patient's outlook for survival.

Although giving radiation therapy following surgery (adjuvant therapy) may reduce the risk of local recurrence, no study has shown that this will improve survival. The cancer can still come back in distant organs. This suggests that the cancer cells may have spread through the bloodstream before the cancer was removed. Adjuvant chemotherapy may be recommended in some patients with stage III cancer. The goal of adjuvant chemotherapy is to destroy these cells before they grow into tumors large enough to cause problems or large enough to be recognized by imaging tests. Early results from studies of adjuvant chemotherapy have not yet shown any improvement in survival rates, but these studies are still in progress. Entering a clinical trial, if one is available, would be a good option. Women with endometrial stromal sarcomas might receive hormonal treatment instead of chemotherapy after surgery.

**Stage IV:** There is currently no standard treatment for these cancers. Surgery or pelvic radiation (or both) is sometimes done, as in less advanced stages. 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, progesterone-like drugs or estrogen-blocking drugs may be helpful.

**Recurrent uterine sarcoma:** Treatment options are the same as with stage IV. Unfortunately, this type of cancer has a strong tendency to recur. If a recurrent pelvic tumor is large and causing discomfort, radiation may be used to reduce the size of the tumor and relieve the symptoms. Sometimes, if the cancer comes back in the lungs, and there are only one or two small tumors, these can be removed with surgery. Some patients have been cured by this treatment.

## More Treatment Information

For more details on treatment options -- 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 19 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 American Cancer Society collaborates with the NCCN to produce a version of some of these treatment guidelines, written specifically for patients and their families. These less-technical versions are available on both the NCCN Web site ([www.nccn.org](http://www.nccn.org)) and the ACS Web site ([www.cancer.org](http://www.cancer.org)). A print version can also be requested from the ACS at 1-800-ACS-2345.

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?
- 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. Even with no recurrences, people who have had cancer learn to live with uncertainty.

### 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. Many people have been bankrupted by cancer recurrence.

## **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 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 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-ACS-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 the publication, "Cancer Related Fatigue and Anemia Treatment Guidelines for Patients.")

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 take part in at least 1 physical activity 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 your treatment.

Now you may find that you think about the potential 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-ACS-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 can be 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. Scientists expect that these discoveries 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. For example, packaging doxorubicin inside tiny fat droplets called liposomes may make the drug more effective, while also reducing certain side effects. 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 are derivatives of marine compounds.

## 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-ACS-2345:

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

Sexuality & Cancer: For the Woman Who Has Cancer and Her Partner (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-ACS-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  
Telephone 1-800-444-4441  
Internet address: [www.thegcf.org](http://www.thegcf.org)

National Cancer Institute  
Telephone: 1-800-4-CANCER (1-800- 422-6237) or TTY 1-800-332-8615  
Internet address: [www.cancer.gov](http://www.cancer.gov)

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

The American Cancer Society is happy to address almost any cancer-related topic. If you have any more questions, please call us at 1-800 ACS 2345 at any time, 24 hours a day.

## References

American Cancer Society. *Cancer Facts and Figures 2008*. Atlanta, Ga: American Cancer Society; 2008.

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.

Burke TW, Mundt AJ, Muggia FM. Cancers of the uterine body. In: DeVita VT, Hellman S, Rosenberg SA, eds. *Cancer: Principles and Practice of Oncology*. Philadelphia, Pa: Lippincott Williams & Wilkins 2005:1341-1359.

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.

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.

PDQ database. Uterine sarcoma. Bethesda, Md: National Cancer Institute; Accessed July, 2005. Available at [www.cancer.gov](http://www.cancer.gov).

National Comprehensive Cancer Network. Uterine Sarcoma. [www.nccn.org](http://www.nccn.org). Accessed July, 2005.

Last Medical Review: 7/19/2006

Last Revised: 4/23/2008

2006 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)