



Uterine Sarcoma

What is cancer?

The body is made up of trillions of living cells. Normal body cells grow, divide to make new cells, and die in an orderly way. 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. In most cases the cancer cells form a tumor. Cancer cells can also grow into (invade) 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 is 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 abnormal cell does.

People can inherit damaged DNA, but most often the 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.

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 (and treated) based on the place where it started. For example, breast cancer that has spread to the liver is still called breast

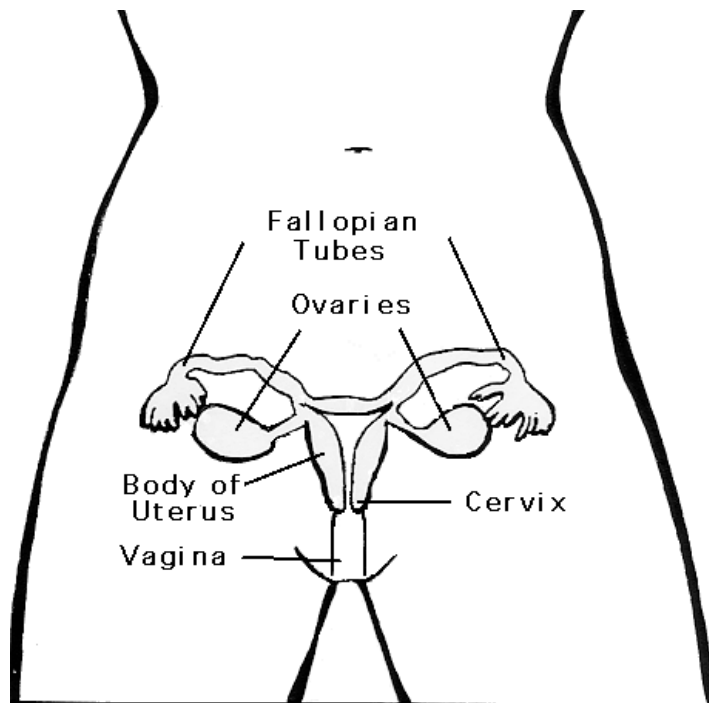
cancer, not liver cancer. Likewise, prostate cancer that has spread to the bone is still prostate cancer, not bone cancer.

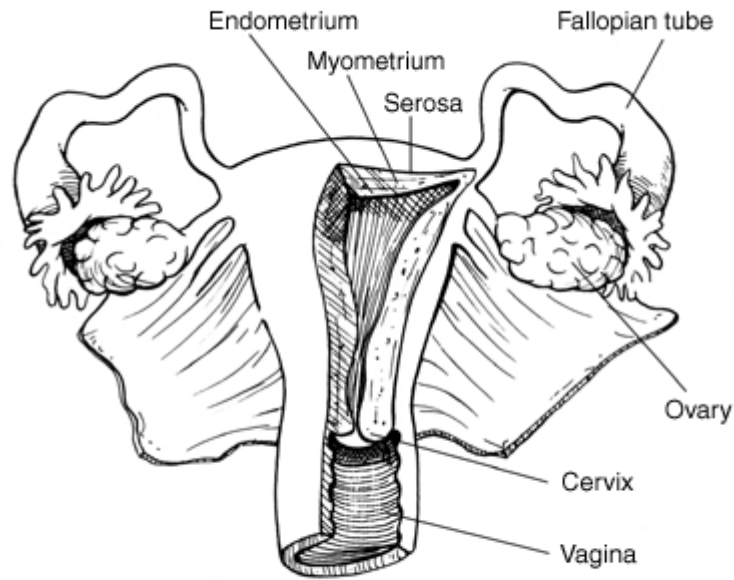
Different types of cancer can behave very differently. They grow at different rates and respond to different treatments. That is why people with cancer need treatment that is aimed at their particular kind of cancer.

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 can't invade other tissues. Because they can't invade, they also can't spread to (metastasize) other parts of the body. 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 a baby out during childbirth.

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 cancers are discussed in our other

documents *Cervical Cancer* and *Endometrial (Uterine) Cancer*. This document is only about *uterine sarcomas*.

Most uterine sarcomas are put into 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 less than 1% (1 in 100) of all uterine cancers. These tumors are low grade -- the cancer cells do not look very abnormal and they tend to grow slowly. Patients with these tumors have a better outlook than those with other uterine sarcomas .
- **Undifferentiated sarcomas** used to be considered a type of endometrial stromal sarcoma, but since they are more aggressive and are treated differently from low-grade tumors, they are now considered separately. These cancers make up less than 1% of all uterine cancers and tend to have a poor outlook.
- **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 *Endometrial (Uterine) Cancer*.

Benign uterine 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 types of *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 a *myomectomy*. Some treatments 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. This surgery is 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 estimates for cancer of the uterine corpus (body of the uterus) in the United States for 2015 are:

- About 54,870 new cases of cancer of the uterine corpus will be diagnosed, but only about 1,600 of these cases will be uterine sarcomas.
- About 8,590 women in the United States will die from cancer of the uterine corpus.

What are the risk factors for uterine sarcoma?

A risk factor is anything that affects 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 cells' 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.

RB gene changes

Women who have had a type of eye cancer called *retinoblastoma* that was caused by being born with an abnormal copy of the *RB* gene have an increased risk of getting uterine leiomyosarcomas.

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. Research continues 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 main types of uterine sarcoma are different. (See "How is uterine sarcoma diagnosed?")

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*.

Signs and symptoms of uterine sarcomas

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. Still, if you are having these problems, you should see a doctor to see find the cause and get any needed treatment.

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 other than 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 and undifferentiated sarcomas.

Vaginal discharge

About 10% of women with uterine sarcomas have a vaginal discharge that does not have 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 a 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 might have a feeling of fullness in your pelvis.

How is uterine sarcoma diagnosed?

Some uterine sarcomas are diagnosed during or after surgery for what is thought to be benign fibroid tumors. Most, though, are diagnosed because of symptoms.

If you have symptoms of uterine cancer, the first step is to see your doctor. He or she will examine you and may order some tests.

Consultation, 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. If your doctor suspects cancer, you may be referred to a gynecologist or a doctor specializing in cancers of the female reproductive system (gynecologic oncologist).

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 removed by endometrial biopsy or by dilation and curettage (D&C). Often a hysteroscopy is done with the D&C (see below).

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 and undifferentiated sarcomas, but less than half of leiomyosarcomas (abbreviated LMSs). These tests don't find all LMSs because these cancers begin in the muscle layer of the wall of the uterus. 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 removing it (with surgery).

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 the uterine lining (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 or regional anesthesia is sometimes used (with general anesthesia, drugs are given that put you into a deep sleep and keep you from feeling pain; regional anesthesia is a nerve block that numbs a larger area of the body).

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 is usually done in the outpatient surgery area of a clinic or hospital. This procedure is done while the woman is under general or regional 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 the endometrial 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 a 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 its grade.

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 have *estrogen receptors* and *progesterone receptors*. These hormone receptors are found on many endometrial stromal sarcomas. Cancers with estrogen receptors on the cells are more likely to grow in response to estrogen, while those with progesterone receptors often have their growth decreased by progesterone. These cancers may stop growing (or even shrink) when treated with certain hormone drugs. Checking for these receptors helps predict which patients will benefit from treatment with these drugs.

Cystoscopy and proctoscopy

If a woman has signs or symptoms that suggest 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. They 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 CT scan is an x-ray test that produces detailed cross-sectional images of your body. Instead of taking one picture, like a standard 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.

A CT scanner has been described as a large donut, with a narrow table in the middle opening. You will need to lie still on the table while the scan is being done. CT scans take longer than regular x-rays, and you might feel a bit confined by the ring while the pictures are being taken.

Before the test, 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 line through which a different kind of contrast dye (IV contrast) is injected. This helps better outline structures such as blood vessels in your body.

The injection can cause some flushing (redness and warm feeling). A few people are allergic to the dye and get hives or, rarely, have more serious reactions like trouble breathing and low blood pressure. Be sure to tell the doctor if you have any allergies or 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-guided needle biopsy: CT scans can also be used to guide a biopsy needle precisely into a suspected tumor. For this procedure, the patient remains on the CT scanning table while the doctor advances a biopsy needle through the skin and toward the tumor. CT scans are repeated until the needle is within the mass. A fine needle biopsy sample or a larger core needle biopsy sample is then removed to be looked at under a microscope. This isn't used to biopsy tumors of the uterus, but can be used to biopsy suspected areas of metastasis.

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 also 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. Because many 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 routinely used to work-up a pelvic mass or abnormal bleeding in patients who are not known to have cancer.

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 an 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 systems used for staging uterine sarcoma, the *FIGO* (International Federation of Gynecology and Obstetrics) system and the American Joint Committee on Cancer TNM staging system, are the same.

Staging is based on: the size or extent of the tumor (T), whether the cancer has spread to lymph nodes (N) and whether it has spread to distant sites (M). Uterine sarcoma is staged based on examination of tissue removed during an operation. This is known as *surgical staging* and means that doctors can't tell for sure what stage the cancer is in until after surgery is done (in most cases). The staging system classifies the cancer in stages I through IV, with each of these stages being further divided by letters (for example, stages IIA and IIB).

The staging system looks at how far the cancer has spread:

- It can spread **locally** to other parts of the uterus and to tissues of the pelvis, including the fallopian tubes, ovaries, and tissue near the uterus.
- It can also spread **regionally** to nearby lymph nodes (bean-sized organs that are part of the immune system) and other parts of the pelvis. 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 the para-aortic nodes.

- Finally, the cancer can spread to **distant** lymph nodes or organs such as the lungs, liver, bone, brain, and others.

Tumor extent (T)

T0: No signs of a tumor in the uterus can be found.

T1: The tumor is growing in the uterus, but has not started growing outside the uterus.

- **T1a:** The tumor is only in the uterus and is no larger than 5 cm across (5 cm is about 2 inches).
- **T1b:** The tumor is only in the uterus and is larger than 5 cm across.

T2: The tumor is growing outside the uterus but is not growing outside of the pelvis.

- **T2a:** The tumor is growing into the adnexa (the ovaries and fallopian tubes).
- **T2b:** The tumor is growing into tissues of the pelvis other than the adnexa.

T3: The tumor is growing into tissues of the abdomen.

- **T3a:** The tumor is growing into tissues of the abdomen in one place only.
- **T3b:** The tumor is growing into tissues of the abdomen in 2 or more places.

T4: The tumor is growing into the bladder or rectum.

Lymph node spread (N)

NX: Spread to nearby lymph nodes cannot be assessed.

N0: The cancer has not spread to nearby lymph nodes.

N1: Cancer has spread to nearby lymph nodes.

Distant spread (M)

M0: The cancer has not spread to distant lymph nodes, organs, or tissues.

M1: The cancer has spread to distant organs (such as the lungs or liver).

Stage grouping

Information about the tumor, lymph nodes, and any cancer spread is combined to assign the stage of disease. This process is called *stage grouping*. The stages are described using Roman numerals from I to IV. Some stages are divided into sub-stages indicated by letters.

Stage I (T1, N0, M0): The cancer is only in the uterus (T1). It has not spread to lymph nodes (N0) or distant sites (M0).

- **Stage IA (T1a, N0, M0):** The cancer is only in the uterus and is no larger than 5 cm across (T1a). It has not spread to nearby lymph nodes (N0) or distant sites (M0).
- **Stage IB (T1b, N0, M0):** The cancer is only in the uterus and is larger than 5 cm across (T1b). It has not spread to nearby lymph nodes (N0) or distant sites (M0).

Stage II (T2, N0, M0): The cancer is growing outside the uterus but is not growing outside of the pelvis (T2). The cancer has not spread to nearby lymph nodes (N0) or distant sites (M0).

- **Stage IIA (T2a, N0, M0):** The cancer is growing into the adnexa (the ovaries and fallopian tubes) (T2a). It has not spread to nearby lymph nodes (N0) or distant sites (M0).
- **Stage IIB (T2b, N0, M0):** The cancer is growing into tissues of the pelvis other than the adnexa (T2b). It has not spread to nearby lymph nodes (N0) or distant sites (M0).

Stage III: Any of the following:

- **Stage IIIA (T3a, N0, M0):** The cancer is growing into tissues of the abdomen in one place only (T3a). It has not spread to nearby lymph nodes (N0) or distant sites (M0).
- **Stage IIIB (T3b, N0, M0):** The cancer is growing into tissues of the abdomen in 2 or more places (T3b). It has not spread to lymph nodes (N0) or distant sites (M0).
- **Stage IIIC (T1 to T3, N1, M0):** The cancer in the uterus can be any size and may have grown into tissues in the pelvis and/or abdomen. It has not spread to the bladder or rectum (T1 to T3). The cancer has spread to lymph nodes near the uterus (pelvic and/or para-aortic lymph nodes) (N1). It has not spread to distant sites (M0).

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

- **Stage IVA (T4, any N, M0):** The cancer has spread to the rectum or urinary bladder (T4). It may also be in the lymph nodes (any N) but has not spread to distant sites (M0).
- **Stage IVB (any T, any N, M1):** The cancer in the uterus can be any size and may or may not have grown into tissues in the pelvis and/or abdomen (including the bladder or rectum) (any T). The cancer may or may not have spread to lymph nodes near the uterus

(any N). 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 (M1).

Survival rates for uterine sarcoma, by stage

Survival rates are often used by doctors as a standard way of discussing a person's prognosis (outlook). Some patients with cancer may want to know the survival statistics for people in similar situations, while others may not find the numbers helpful, or may even not want to know them. If you decide that you do not want to know about the survival rates for uterine sarcoma given in the next few paragraphs, skip to the next section.

The 5-year survival rate refers to the percentage of patients who live at least 5 years after their cancer is diagnosed. Of course, many people live much longer than 5 years (and many are cured).

Five-year *relative* survival rates compare the survival of people with the cancer to the survival for people without the cancer. This is a way to take into account deaths from causes other than cancer. The 5-year relative survival rate is a better way to describe the impact of a particular type and stage of cancer on survival.

In order to get 5-year survival rates, doctors have to look at people who were treated at least 5 years ago. Improvements in treatment since then may result in a more favorable outlook for people now being diagnosed with uterine sarcoma.

Survival rates are often based on previous outcomes of large numbers of people who had the disease, but they cannot predict what will happen in any particular person's case. Many factors may affect a person's outlook, such as:

- 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 woman's general state of health
- The treatment received

Your doctor can tell you how the numbers below may apply to you, as he or she is familiar with your particular situation.

The survival statistics noted below come from the National Cancer Institute's SEER program. They are based on women diagnosed with uterine sarcomas from 2004 to 2010. SEER doesn't break down these statistics by AJCC or FIGO stage. Instead, SEER uses something called summary stages: localized, regional, and distant.

- Localized means the cancer is only in the uterus, and corresponds to stage I.

- Regional means the cancer has spread to nearby tissues or lymph nodes and includes stages II, and III.
- Distant means the cancer has spread further and includes stages IVA and IVB.

Leiomyosarcoma

Stage	5-Year Relative Survival
Localized	63%
Regional	36%
Distant	14%

Undifferentiated sarcoma

Stage	5-Year Relative Survival
Localized	70%
Regional	43%
Distant	23%

Endometrial stromal sarcoma:

Stage	5-Year Relative Survival
Localized	99%

Regional	94%
Distant	69%

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 could 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. While you are 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 handle. They want to answer your questions, so ask them! See “What should you ask your doctor about uterine sarcoma” for possible questions to ask.

You might 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.

These are the 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—or treatments—are 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, chemotherapy, 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.

For information about some of the most common approaches used based on the extent of the disease, see the section “Treatment options for uterine sarcoma, by stage.”

Surgery for uterine sarcomas

Surgery is the main (primary) treatment for uterine sarcoma. The major goal of surgery is to remove all of the cancer. This usually means removing the uterus, but in some cases 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 (see “How is uterine sarcoma staged?”). 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, MRIs, chest X-rays and ultrasound, as well as a 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—officially 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 an incision in the front of the abdomen, the surgery is called an *abdominal hysterectomy*. When the uterus is removed through the vagina, it is called a *vaginal hysterectomy*. If the lymph nodes need to be removed and tested, 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 a thin lighted tube with a video camera at the end. It can be inserted into the body through a small incision (cut) and allows the doctor to see inside the patient without making a big incision. The doctor can use surgical instruments that are inserted through other small incisions to operate. The 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, sometimes using a robot, as well. Laparoscopic procedures require less recovery time than a regular abdominal hysterectomy but often the surgery takes longer. You should talk with your surgeon about what approach will be used and why it is the best for you.

Either general or regional anesthesia is used for the procedure--this means that the patient is asleep or sedated and numb from the waist down. 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 2 to 3 weeks recovery. After a hysterectomy, a woman cannot become pregnant and give birth to children. Surgical complications are uncommon but could include excessive bleeding, wound infection, and damage to the urinary or intestinal systems.

Radical hysterectomy

This operation removes the entire uterus as well as the tissues next to the uterus and cervix (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.

Radical hysterectomy is most often done through an abdominal surgical incision, although it can also be performed through the vagina or laparoscopically with or without the assistance of the DaVinci[®] robot. Most patients undergoing a radical hysterectomy also have some lymph nodes removed, either through the abdominal incision or laparoscopically. 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. The surgery leaves the woman unable to become pregnant and give birth to children. Complications are similar to, but more common than those associated with a simple hysterectomy and could include excessive bleeding, wound infection, and damage to the urinary or intestinal systems. If some of the nerves of the bladder are damaged, a catheter will be needed to empty the bladder for some time after surgery. This usually improves and the catheter can be removed later.

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. 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 sarcoma to grow, many doctors are concerned that it could increase the chance of the cancer coming back. Most experts in this field consider estrogen therapy 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 estrogen therapy with her doctor before making a decision. Other treatments can be used to help relieve symptoms of menopause and prevent osteoporosis that do not affect the risk of the cancer coming back.

Lymph node surgery

Your surgeon may do a procedure called a *lymph node dissection* or a *lymph node sampling*, which removes 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). 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.

Removing lymph nodes in the pelvis can lead to a buildup of fluid in the legs, a condition called *lymphedema*. This occurs more often if radiation is given after surgery. More information about lymphedema can be found in our document *Understanding Lymphedema for Cancers Other Than Breast Cancer*.

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 at the same time the hysterectomy is done 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

If you are premenopausal, removing your uterus causes menstrual bleeding (periods) to stop. If your ovaries are also removed, you will go into menopause. This can lead to vaginal dryness and pain during intercourse. These symptoms can be improved with estrogen treatment, but women who have been treated for certain cancers may need to avoid this hormone. Other medicines may be helpful for those women.

While physical and emotional changes can affect the desire for sex, these surgical procedures 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 had 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 for uterine sarcomas

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 be given before surgery to make it easier to completely remove the cancer. Radiation may also be given after surgery to lower the chance of the cancer coming back in the pelvis. This is called *adjuvant radiation*. It 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 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 is usually given 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. The length of the cylinder (and the amount of the vagina treated) can vary, but the upper part of the vagina is always treated. With this method, the radiation mainly affects the vagina in the area in contact with the cylinder. Nearby structures such as the bladder and rectum get less 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 radiation sources are usually left in place for between 1 and 4 days at a time. The patient needs to stay immobile to keep the radiation sources from moving during treatment, and so she is usually kept in the hospital on strict bed rest. More than one treatment 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

Short-term side effects of radiation therapy include:

- Tiredness
- Nausea and vomiting

- Loose stools or diarrhea
- Skin changes
- Low blood counts

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.

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.

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

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.

Long-term side effects of radiation

Radiation can also lead to some side effects that can last a long time.

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. For more information about dealing with the sexual side effects of radiation, see our document *Sexuality for the Woman With Cancer*.

Pelvic radiation can damage the ovaries, resulting in premature menopause. However, most women being treated for uterine sarcoma have already gone through menopause, either naturally or as a result of surgery to treat the cancer.

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. More information about lymphedema can be found in our document *Understanding Lymphedema for Cancers Other Than Breast Cancer*.

Pelvic radiation can also weaken 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.

For more information, see our document *Understanding Radiation Therapy: A Guide for Patients and Families*.

Chemotherapy for uterine sarcomas

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.

Some of the drugs used to treat uterine sarcomas include:

- Cisplatin
- Dacarbazine (DTIC)
- Docetaxel (Taxotere[®])
- Doxorubicin (Adriamycin[®])
- Liposomal doxorubicin (Doxil[®])
- Epirubicin (Ellence[®])
- Gemcitabine (Gemzar[®])
- Ifosfamide (Ifex[®])
- Paclitaxel (Taxol[®])

- Temozolomide (Temodar[®])
- Vinorelbine (Navelbine[®])

Often a combination of drugs is used. For example, gemcitabine and docetaxel are often used together to treat leiomyosarcoma.

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 can be 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.

If you'd like more information on a drug used in your treatment or a specific drug mentioned in this section, see our [Guide to Cancer Drugs](#) , or call us with the names of the medicines you're taking.

For more information on chemotherapy, see our document *A Guide to Chemotherapy*.

Hormone therapy for uterine sarcomas

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 types of uterine sarcomas.

Progestins

Progestins are drugs that act like the hormone progesterone. The progestins used most often to treat uterine sarcoma are megestrol (Megace[®]) and medroxyprogesterone (Provera[®]). 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[®]) and leuprolide (Lupron[®]). 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, 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[®]), anastrozole (Arimidex[®]), and exemestane (Aromasin[®]). These drugs are most often used to treat breast cancer, but they also might be helpful in treating endometrial stromal sarcoma. Because they don't affect estrogen production by the ovaries, they are only useful in women whose ovaries have been removed or no longer work (like after menopause). Side effects can include any of the symptoms of menopause, such as hot flashes and vaginal dryness, as well as joint/muscle pain. If they are taken for a long time (years), these drugs can weaken bones, sometimes leading to osteoporosis.

Clinical trials for uterine sarcomas

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 website at www.cancer.org/clinicaltrials. 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 website at www.cancer.gov/clinicaltrials.

You must meet requirements 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. In some cases they may be the only way to get access to newer treatments. They are also 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 website or call our toll-free number and have it sent to you.

Complementary and alternative therapies for uterine sarcomas

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 websites may 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 few or 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 for uterine sarcoma, 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 (chemo), 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 uterine sarcoma is rare, it has been hard to study it well.

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

Leiomyosarcoma and undifferentiated sarcoma

Stages I and II: 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 may also be done. During surgery, organs near the uterus and the thin membrane that lines the pelvic and abdominal cavities (peritoneum) 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. It may also be possible to leave a young woman's ovaries in place (but remove the uterus and fallopian tubes), since it isn't clear that this will lead to worse outcomes. Still, this is not a standard treatment, and you should discuss the possible risks and benefits with your doctor. In either case, close follow-up is important, and additional surgery may be needed if the cancer comes back.

After surgery, treatment with radiation (or sometimes chemo) may be recommended. This is called *adjuvant treatment* and 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.

For LMS of the uterus, adjuvant radiation may lower the chance of the cancer growing back in the pelvis (called *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 giving chemo after surgery (adjuvant chemotherapy) for stage II cancers. Chemo is sometimes recommended for stage I LMS as well, but it is less clear that it is really helpful. 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 this treatment really helps women live longer. Studies of adjuvant therapy are still in progress. For anyone being treated for uterine LMS, entering a clinical trial is always a good option.

Stage III: Surgery is done to remove all of the cancer. This includes removing the uterus (a hysterectomy), removing both fallopian tubes and ovaries (bilateral salpingo-oophorectomy),

and lymph node dissection or sampling. If the tumor has spread to the vagina (stage IIIB), part (or even all) of the vagina will need to be removed as well.

After surgery, treatment with radiation (with or without chemo) may be offered to lower the chance that the cancer will come back.

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

Stage IV is divided into stage IVA and stage IVb.

Stage IVA cancers have spread to nearby organs and tissues, such as the bladder or rectum. These cancers may be able to be completely removed with surgery, and this is usually done if possible. If the cancer cannot be removed completely, radiation may be given, either alone or with chemo.

Stage IVB cancers have spread outside of the pelvis, most often to the lungs, liver, or bone. There is currently no standard treatment for these cancers. Chemo may be able to shrink the tumors for a time, but is not thought to be able to cure the cancer. Radiation therapy may also be an option.

Women with stage IV uterine sarcomas might consider taking part in clinical trials (scientific studies of promising treatments) testing new chemo or other treatments.

Endometrial stromal sarcoma

Stages I and II: Early stage endometrial stromal sarcoma is treated with surgery: hysterectomy and bilateral salpingo-oophorectomy (removal of the uterus, both fallopian tubes and both ovaries). Some young women may be given the option of keeping their ovaries, but this is not the standard treatment. Pelvic lymph nodes may be removed as well. After surgery, some women do not get further treatment. These women are watched closely for signs that the cancer has returned. Others may be treated with hormone therapy and sometimes radiation to the pelvis. These can lower the chances of the cancer coming back, but they have not been shown to help patients live longer.

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

Stage III: Surgery is done to remove all of the cancer. This includes removing the uterus (a hysterectomy), removing both fallopian tubes and ovaries (bilateral salpingo-oophorectomy), and lymph node dissection or sampling. 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.

Women with endometrial stromal sarcomas might receive radiation, hormone therapy, 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 is divided into stage IVA and stage IVb.

Stage IVA cancers have spread to nearby organs and tissues, such as the bladder or rectum. These cancers may be able to be completely removed with surgery, and this is usually done if possible. If the cancer cannot be removed completely, radiation may be given, either alone or with chemo. Hormone therapy is also an option.

Stage IVB cancers have spread outside of the pelvis, most often to the lungs, liver, or bone. Hormone therapy can help for a time. Chemo and radiation are also options.

Women with stage IV uterine sarcomas might consider taking part in clinical trials (scientific studies of promising treatments) testing new chemo or other treatments.

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 uterine sarcomas

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 website (www.nccn.org).

The NCI provides treatment guidelines via its telephone information center (1-800-4-CANCER) and its website (www.cancer.gov). Detailed guidelines intended for use by cancer care professionals are also available on 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 my uterus?
- What is the stage of my cancer and what does that mean for me?
- What treatments are appropriate for me? What do you recommend? Why?
- Can I be evaluated by a gynecologic oncologist?
- Am I eligible for a clinical trial?
- 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 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?

For some people with cancer, treatment may remove or destroy the cancer. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about cancer coming back. (When cancer comes back after treatment, it is called *recurrence*.) This is a very common concern in people who have had cancer.

It may take a while before your fears lessen. But it may help to know that many cancer survivors have learned to live with this uncertainty and are living full lives. Our document *Living With Uncertainty: The Fear of Cancer Recurrence* gives more detailed information on this.

For other people, the cancer may never go away completely. These people may get regular treatments with chemotherapy, radiation therapy, or other therapies to try to help keep the cancer in check. Learning to live with cancer that does not go away can be difficult and very stressful. It has its own type of uncertainty. Our document *When Cancer Doesn't Go Away* talks more about this.

Follow-up care

When treatment ends, your doctors will still want to watch you closely. It is very important to go to all of your follow-up appointments. During these visits, your doctors will ask questions about any problems you may have and may do exams and lab tests or x-rays and scans to look for signs of cancer or treatment side effects. Almost any cancer treatment can have side effects. Some may last for a few weeks to months, but others can last the rest of your life. This is the time for you to talk to your cancer care team about any changes or problems you notice and any questions or concerns you have.

It is important to keep health insurance. Tests and doctor visits cost a lot, and even though no one wants to think of their cancer coming back, this could happen.

Should your cancer come back, our document *When Your Cancer Comes Back: Cancer Recurrence* can give you information on how to manage and cope with this phase of your treatment.

Seeing a new doctor

At some point after your cancer diagnosis and treatment, you may find yourself seeing a new doctor who does not know anything about your medical history. It is important that you be able to give your new doctor the details of your diagnosis and treatment. Gathering these details soon after treatment may be easier than trying to get them at some point in the future. Make sure you have this information handy:

- A copy of your pathology report(s) from any biopsies or surgeries
- 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 doctors prepare when patients are sent home from the hospital
- If you had chemotherapy (including hormone therapy), a list of the drugs, drug doses, and when you took them
- Copies of any imaging tests (such as CTs or MRIs) – these can often be put on a CD or DVD

The doctor may want copies of this information for his records, but always keep copies for yourself.

Lifestyle changes after having a uterine sarcoma

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 choices to help you stay healthy and feel as well as you can. This can 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 start during cancer treatment.

Making healthier choices

For many people, a diagnosis of cancer helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try to eat better or get more exercise. Maybe you could cut down on the alcohol, or give up tobacco. Even things like keeping your stress level under control may help. Now is a good time to think about making changes that can have positive effects for the rest of your life. You will feel better and you will also be healthier.

You can start by working on those things that worry you most. 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 for information and support. This tobacco cessation and coaching service can help increase your chances of quitting for good.

Eating better

Eating right can be hard for anyone, but it can get even tougher during and after cancer treatment. Treatment may change your sense of taste. Nausea can be a problem. You may not feel like eating and lose weight when you don't want to. Or you might have gained weight that you can't seem to lose. All of these things can be very frustrating.

If treatment caused weight changes or eating or taste problems, do the best you can and keep in mind that these problems usually get better over time. You may find it helps to eat small portions every 2 to 3 hours until you feel better. You may also want to ask your cancer team about seeing a dietitian, an expert in nutrition who can give you ideas on how to deal with these treatment side effects.

One of the best things you can do after cancer treatment is start healthy eating habits. You may be surprised at the long-term benefits of some simple changes, like increasing the variety of healthy foods you eat. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol intake may lower your risk for a number of types of cancer, as well as having many other health benefits.

Rest, fatigue, and exercise

Extreme tiredness, called *fatigue*, is very common in people treated for cancer. This is not a normal tiredness, but a "bone-weary" exhaustion that doesn't get better with rest. For some people, fatigue lasts a long time after treatment, and can make it hard for them to exercise and do other things they want to do. But exercise can help reduce fatigue. Studies have shown that patients who follow an exercise program tailored to their personal needs feel better physically and emotionally and can cope better, too.

If you were sick and not very active during treatment, it is normal for your fitness, endurance, and muscle strength to decline. Any plan for physical activity should fit your own situation. A person who has never exercised will not be able to take on the same amount of exercise as someone who plays tennis twice a week. If you haven't been active in a few years, you will have to start slowly – maybe just by taking short walks.

Talk with your health care team before starting anything. Get their opinion about your exercise plans. Then, try to find an exercise buddy so you're not doing it alone. Having family or friends involved when starting a new activity can give you that extra boost of support to keep you going when the push just isn't there.

If you are very tired, you will need to balance activity with rest. It is OK to rest when you need to. Sometimes it's really hard for people to allow themselves to rest when they are used to working all day or taking care of a household, but this is not the time to push yourself too hard. Listen to your body and rest when you need to. For more information on dealing with fatigue, please see *Fatigue in People With Cancer* and *Anemia in People With Cancer*. The section "Additional resources for uterine sarcoma" has a list of some other documents about side effects and symptoms that you may find helpful.

Keep in mind exercise can improve your physical and emotional health.

- It improves your cardiovascular (heart and circulation) fitness.
- Along with a good diet, it will help you get to and stay at a healthy weight.

- It makes your muscles stronger.
- It reduces fatigue and helps you have more energy.
- It can help lower anxiety and depression.
- It can make you feel happier.
- It helps you feel better about yourself.

And long term, we know that getting regular physical activity plays a role in helping to lower the risk of some cancers, as well as having other health benefits.

How does having a uterine sarcoma affect your emotional health?

When treatment ends, you may find yourself overcome with many different 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 each day. Now it may feel like a lot of other issues are catching up with you.

You may find yourself thinking about death and dying. Or maybe you're more aware of the effect the cancer has on your family, friends, and career. You may take a new look at your relationship with those around you. Unexpected issues may also cause concern. For instance, as you feel better and have fewer doctor visits, you will see your health care team less often and have more time on your hands. These changes can make some people anxious.

Almost everyone who has been through cancer can benefit from getting some type of 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 one-on-one counselors. 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 good for you to try to deal with everything on your own. And your friends and family may feel shut out if you do not 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 a group or resource that may work for you.

If treatment for uterine sarcoma stops working

If cancer keeps growing or comes back after one kind of treatment, it is possible that another treatment plan might still cure the cancer, or at least shrink it enough to help you live longer and feel better. But when a person has tried many different treatments and the cancer has not gotten any better, the cancer tends to become resistant to all treatment. If this happens, it's important to weigh the possible limited benefits of a new treatment against the possible downsides. Everyone has their own way of looking at this.

This is likely to be the hardest part of your battle with cancer -- when you have been through many medical treatments and nothing's working anymore. Your doctor may offer you new options, but at some point you may need to consider that treatment is not likely to improve your health or change your outcome or survival.

If you want to continue to get treatment for as long as you can, you need to think about the odds of treatment having any benefit and how this compares to the possible risks and side effects. In many cases, your doctor can estimate how likely it is the cancer will respond to treatment you are considering. For instance, the doctor may say that more chemo or radiation might have about a 1% chance of working. Some people are still tempted to try this. But it is important to think about and understand your reasons for choosing this plan.

No matter what you decide to do, you need to feel as good as you can. Make sure you are asking for and getting treatment for any symptoms you might have, such as nausea or pain. This type of treatment is called *palliative care*.

Palliative care helps relieve symptoms, but is not expected to cure the disease. It can be given along with cancer treatment, or can even be cancer treatment. The difference is its purpose - the main purpose of palliative care is to improve the quality of your life, or help you feel as good as you can for as long as you can. Sometimes this means using drugs to help with symptoms like pain or nausea. Sometimes, though, the treatments used to control your symptoms are the same as those used to treat cancer. For instance, radiation might be used to help relieve bone pain caused by cancer that has spread to the bones. Or chemo might be used to help shrink a tumor and keep it from blocking the bowels. But this is not the same as treatment to try to cure the cancer.

At some point, you may benefit from hospice care. This is special care that treats the person rather than the disease; it focuses on quality rather than length of life. Most of the time, it is given at home. Your cancer may be causing problems that need to be managed, and hospice focuses on your comfort. You should know that while getting hospice care often means the end of treatments such as chemo and radiation, it doesn't mean you can't have treatment for the problems caused by your cancer or other health conditions. In hospice the focus of your care is on living life as fully as possible and feeling as well as you can at this difficult time. You can learn more about hospice in our document called *Hospice Care*.

Staying hopeful is important, too. 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. Pausing at this time in your cancer treatment gives you a chance to refocus on the most important things in your life. Now 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. Though the cancer may be beyond your control, there are still choices you can make.

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. Many endometrial stromal sarcomas (ESSs) have abnormalities in chromosomes 6, 7, or 17. Often, there is an abnormal “swapping” of 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/JJAZ*. This gene may help the cells to become malignant. Finding it can confirm the diagnosis of ESS. A different translocation, called *YWHAE/FAM22* occurs in undifferentiated uterine sarcomas (high-grade stromal sarcomas). Cancers with the *YWHAE/FAM22* translocation tend to grow and spread more aggressively than those with the *JAZF1/JJAZ* translocation.

Scientists expect that discoveries such as these 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[®]) has been approved to treat sarcoma in Europe, but is still being studied in the United States. Another drug, temozolomide, which is approved to treat brain tumors, also seems to help women with uterine leiomyosarcomas. Adjuvant radiation and chemotherapy continue to be evaluated for treatment of uterine sarcomas. New compounds are also being evaluated for soft-tissue sarcomas and may help women with uterine sarcomas. Some of these compounds act differently from traditional chemotherapy drugs and are called targeted therapies.

Additional resources for uterine sarcoma

More information from your American Cancer Society

Here is more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, www.cancer.org.

Living with Cancer

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

Distress in People With Cancer

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

Guide to Controlling Cancer Pain (also available in Spanish)

When Cancer Doesn't Go Away

When Your Cancer Comes Back: Cancer Recurrence

Understanding cancer treatments

A Guide to Cancer Surgery (also available in Spanish)

A Guide to Chemotherapy (also available in Spanish)

Understanding Radiation Therapy: A Guide for Patients and Families (also available in Spanish)

Cancer treatment side effects

Nausea and Vomiting

Anemia in People With Cancer

Fatigue in People With Cancer

Peripheral Neuropathy Caused by Chemotherapy

Family and caregiver concerns

Talking With Friends and Relatives About Your Cancer (also in Spanish)

What It Takes to Be a Caregiver

Caring for the Patient With Cancer at Home: A Guide for Patients and Families (also available in Spanish)

Helping Children When a Family Member Has Cancer: Dealing With Diagnosis (also available in Spanish)

Work, insurance, and finances

Health Insurance and Financial Assistance for the Cancer Patient

Returning to Work After Cancer Treatment

Working During Cancer Treatment

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at cancer.org/bookstore to find out about costs or to place an order.

National organizations and websites*

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

Foundation for Women's Cancer (formerly the Gynecologic Cancer Foundation)

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

Website: www.foundationforwomenscancer.org/

Offers referrals to gynecologic oncologists and has information about how to prevent, detect, and treat female cancer; also the booklet, "Renewing Intimacy and Sexuality After Gynecologic Cancer." Educational materials are offered online, and educational programs for survivors are offered throughout the country.

National Cancer Institute

Toll-free number: 1-800-4-CANCER (1-800- 422-6237)

Website: www.cancer.gov

Offers current information about cancer screening, diagnosis, and treatment as well as information for the family and children of people with cancer

**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.

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1-800-227-2345 or www.cancer.org