



Kaposi Sarcoma

What is cancer?

The body is made up of trillions of living cells. Normal body cells grow, divide, and die in an orderly fashion. During the early years of a person's life, normal cells divide faster to allow the person to grow. After the person becomes an adult, most cells divide only to replace worn-out or dying cells or to repair injuries.

Cancer begins when cells in a part of the body start to grow out of control. There are many kinds of cancer, but they all start because of out-of-control growth of abnormal cells.

Cancer cell growth is different from normal cell growth. Instead of dying, cancer cells continue to grow and form new, abnormal cells. Cancer cells can also invade (grow into) other tissues, something that normal cells cannot do. Growing out of control and invading other tissues are what makes a cell a cancer cell.

Cells become cancer cells because of damage to DNA. DNA is in every cell and directs all its actions. In a normal cell, when DNA gets damaged the cell either repairs the damage or the cell dies. In cancer cells, the damaged DNA is not repaired, but the cell doesn't die like it should. Instead, this cell goes on making new cells that the body does not need. These new cells will all have the same damaged DNA as the first cell does.

People can inherit damaged DNA, but most DNA damage is caused by mistakes that happen while the normal cell is reproducing or by something in our environment. Sometimes the cause of the DNA damage is something obvious, like cigarette smoking. But often no clear cause is found.

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

Cancer cells often travel to other parts of the body, where they begin to grow and form new tumors that replace normal tissue. This process is called metastasis. It happens when the cancer cells get into the bloodstream or lymph vessels of our body.

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

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

Not all tumors are cancerous. Tumors that aren't cancer are called benign. Benign tumors can cause problems – they can grow very large and press on healthy organs and tissues. But they cannot grow into (invade) other tissues. Because they can't invade, they also can't spread to other parts of the body (metastasize). These tumors are almost never life threatening.

What Is Kaposi sarcoma?

Kaposi sarcoma (KS) is a cancer that develops from the cells that line lymph or blood vessels. The abnormal cells of KS form purple, red, or brown blotches or tumors on the skin. These affected areas are called lesions. The skin lesions of KS may look bad, but in many cases, the lesions cause no symptoms. In other cases, the disease causes painful swelling, especially in the legs, groin area, or skin around the eyes. KS can cause serious problems (or even become life threatening) when the lesions are in the lungs, liver, or digestive tract. KS in the digestive tract, for example, can cause bleeding, while tumors in the lungs may cause difficulty breathing.

Types of Kaposi sarcoma

Some cancers such as lung cancer or breast cancer have several different types that indicate either different types of cells have become cancerous or different types of changes have occurred within a particular cell type. On the other hand, the different types of KS are defined by the different populations it develops in, but the changes within the KS cells are very similar.

Epidemic (AIDS-related) Kaposi sarcoma

The most common type of KS in the United States is *epidemic* or *AIDS-related KS*. This type of KS develops in people who are infected with HIV, the virus that causes AIDS. A person infected with HIV (that is, who is HIV-positive) does not necessarily have AIDS. The virus can be present in the body for a long time, typically many years, before causing major illness. The disease known as AIDS begins when the virus has seriously damaged the immune system, which results in certain types of infections and other medical complications, including KS. When HIV damages the immune system, people who also are infected with a certain virus (the *Kaposi sarcoma herpesvirus* or *KSHV*) are more likely to develop KS. The risk of developing KS is closely linked to the CD4 count. The

CD4 count is a measure of the effect of HIV on the immune system. The lower the CD4 count, the more likely that the patient will get KS.

KS is considered an "AIDS defining" illness. This means that when KS occurs in someone infected with HIV, that person officially has AIDS (and is not just HIV positive).

Treatment of HIV infection with highly active antiretroviral therapy (HAART) has resulted in fewer cases of epidemic KS. It can often keep advanced KS from developing. HAART doesn't completely protect against KS; it can still occur in people whose HIV is well controlled with HAART. Sometimes people on HAART get aggressive KS that requires treatment with chemotherapy, radiation, or some other therapy. Once KS develops it is still important to continue HAART. In areas of the world where HAART is not easy to obtain, KS in AIDS patients can advance quickly and cause death in just 6 months.

Classic (Mediterranean) Kaposi sarcoma

Classic KS occurs in elderly people of Mediterranean, Eastern European, and Middle Eastern heritage. Classic KS is more common in men than in women. Patients typically have one or more lesions on the legs, ankles, or the soles of the feet. Compared to other types of KS, the lesions in this type do not grow as quickly, and new lesions do not develop as often. The people who get classic KS come from areas where KSHV infection is more common than in the United States or Northern Europe. The immune system of people with classic KS is not as weak as it is in those who have epidemic KS, but it may be weaker than normal. Getting older can naturally weaken the immune system a little. When this occurs, people who already have a KSHV infection are more likely to develop KS.

Endemic (African) Kaposi sarcoma

Endemic KS occurs in people living in Equatorial Africa and is sometimes called *African KS*. KSHV infection is much more common in Africa than in other parts of the world, increasing the risk of KS there. There appear to be other factors in Africa that contribute to the development of KS since the disease affects a broader group of people that includes children and women.

Endemic KS tends to occur in younger people (usually under age 40). Rarely a more aggressive form of endemic KS is seen in children before puberty. This type usually affects the lymph nodes and other organs and can lead to death within a year.

Endemic KS used to be the most common type of KS in Africa. Then, as AIDS became more common in Africa, the epidemic type became the most common type seen in that area.

Iatrogenic (transplant-associated) Kaposi sarcoma

When KS develops in people whose immune systems have been suppressed after an organ transplant, it is called *iatrogenic*, or *transplant-associated KS*. Most transplant patients need to take drugs to keep the immune system from rejecting (attacking and killing) the new organ. By weakening the body's immune system, these drugs increase the chance that someone infected with KSHV will develop KS. Stopping the immune suppressing drugs or lowering their dose often makes KS lesions disappear or get smaller.

Kaposi sarcoma in HIV negative men who have sex with men

Recently, there have been reports of KS developing in men who have sex with men who are not infected with HIV. In this group, the cases of KS are often mild, similar to cases of classic KS.

What are the key statistics about Kaposi sarcoma?

Before the AIDS epidemic, Kaposi sarcoma (KS) rarely occurred in the United States. Most often, the types of KS that occurred were classic and iatrogenic. At that time, only about 2 new cases of KS were found for every million people in the United States each year. This changed with the AIDS epidemic.

It has been estimated that an HIV-infected person has a 20,000 times increased risk of developing KS compared with people without HIV. AIDS patients with KS increased the rate of KS in this country more than 20 times — peaking at 47 cases per million people (per year) in the early 1990s. Early in the AIDS epidemic, patients infected with HIV in the United States were estimated to have a 1 in 2 chance of developing KS.

With new treatments for AIDS, KS has become less common in the United States, and it now occurs at a rate of about 7 cases per million people each year. It is still seen most often in people infected with HIV. In the United States, KS is much more common in men than in women, and it is rarely seen in children. It is also more common in African Americans than in whites in the United States. In areas of the world (such as Africa) where Kaposi sarcoma herpesvirus (KSHV) and HIV infection rates are high, both endemic and HIV-associated KS are seen, and KS occurs in men, women, and children.

Transplant recipients are another group that gets KS. About 1 in 200 transplant patients in the United States gets KS. This occurs primarily because they were already infected with KSHV before the transplant; they just didn't have any symptoms. The drugs they take to suppress their immune system allow KS to develop.

Do we know what causes Kaposi sarcoma?

Kaposi sarcoma (KS) is caused by a virus called the *Kaposi sarcoma herpesvirus* (KSHV), also known as *human herpesvirus 8* (HHV8). KSHV belongs to the herpesvirus

family. This virus is similar to Epstein-Barr virus, the virus that causes infectious mononucleosis (mono) and contributes to several types of cancer. In KS, endothelial cells, the cells that line blood and lymphatic vessels, are infected with KSHV. This infection turns them into cancer cells.

Scientists do not yet completely understand how KSHV causes KS, but they do know that the virus brings genetic material into the cells. These genes cause the cells to divide too much and to grow into nearby tissues.

KSHV infection is much more common than KS, and most people infected with this virus do not get KS. The percentage of people infected with KSHV is different in different places around the world. In the United States, studies have found that less than 10% of people are infected with KSHV. The infection is more common in people infected with HIV than in the general population in the United States. The infection rate also varies in different parts of the country. KSHV is more common in men who have sex with men than in men who only have sex with women.

In some areas of Africa, more than 90 % of the population shows signs of KSHV infection. In these areas the virus seems to spread from mother to child. KSHV is more commonly detected in saliva than in other body fluids. Many people infected with KSHV will never show any symptoms. A very small number of those infected will get a mild type of KS. In people whose immune systems are weakened (by AIDS, for example) infection with KSHV is much more likely to lead to KS.

Can Kaposi sarcoma be prevented?

Kaposi sarcoma (KS) is caused by the Kaposi sarcoma herpesvirus (KSHV). There are no vaccines currently available to protect people against KSHV. For now, preventing KS depends on reducing the chance of becoming infected with KSHV and reducing the chance that people who are infected with KSHV will develop KS.

Most cases of KS in the United States occur in people with AIDS. Taking measures to avoid becoming infected with HIV could prevent most cases of KS in this country.

- Since HIV can be spread through sex, avoiding unprotected sex with people infected with HIV could help prevent these infections.
- Since many people don't know that they are infected with HIV, many public health workers recommend using a condom during any sexual contact. (A condom may not be needed if both people are HIV-negative and are in a mutually monogamous relationship). Abstinence is the most effective protection.
- Another way to become infected with HIV is to use contaminated (dirty) needles to inject recreational drugs. Many different public health and law enforcement solutions have been recommended.
- In the past, transfusions of blood and clotting factors were responsible for some HIV infections. As a result of improved HIV testing at blood banks, there is now a very

low risk of HIV infection from blood products in the United States. In some poorer countries, blood products are not tested well, leading to a higher risk of HIV infection with transfusion in those countries.

Patients who are infected with HIV and KSHV, and take the right medicines can reduce their chance of developing KS.

- Testing for HIV can identify those infected with this virus. People with HIV should get treatment to help strengthen their immune system, which usually includes highly active antiretroviral therapy (HAART). HAART reduces the risk of people with HIV developing KS (and AIDS). In addition, treating infections that commonly occur in people with weakened immunity reduces the likelihood of developing problems with KS.
- KSHV is not tested for routinely, but tests are available that could be used to identify HIV-infected patients who are at risk for KS. Studies have shown that HIV-infected people who take several different drugs that block herpesvirus (ganciclovir or foscarnet) are less likely to develop KS because these drugs also work for KSHV. Still, these drugs have serious side effects, and they are only taken to treat certain infections, not to prevent KS.

Can Kaposi sarcoma be found early?

Most cancers start in one place and then spread to other parts of the body. When these cancers are found early, they are more likely to be curable. Kaposi sarcoma (KS) is very different. KS tends to form in several areas at the same time. Even when only one skin lesion is visible, many patients already have other areas of KS that are just too small to be seen.

People infected with HIV should be examined regularly by health care providers who are experienced in recognizing KS and other diseases that go along with HIV infection and AIDS. Patients with symptoms of KS or other AIDS-related problems should tell their doctors right away so treatment can be started as soon as possible.

How is Kaposi sarcoma diagnosed?

Medical history and physical exam

Your doctor will ask about your medical history to learn about any illnesses, operations, your sexual activity, and other possible exposures to Kaposi sarcoma herpesvirus and HIV. The doctor will ask you about symptoms and about any skin tumors you have noticed. The doctor will examine your skin thoroughly and give you a complete physical exam. Sometimes Kaposi sarcoma (KS) lesions develop inside the rectum (the part of the large intestine just inside the anus). A doctor may be able to detect such lesions during an exam with a gloved finger. The doctor may also check the stool for occult (unseen) blood, since KS in the intestines can cause bleeding.

Biopsy

To be sure that a lesion is caused by KS, the doctor will need to take a small sample of tissue from the lesion and send it to a lab to be analyzed. This is called a *biopsy*. Looked at under a microscope, KS cells usually are arranged in a distinctive shape and pattern. Sometimes, though, early lesions may not show the characteristic cell patterns needed to positively diagnose KS.

For skin lesions, the doctor will usually perform a *punch biopsy*, which removes a tiny round piece of tissue. If the entire lesion is removed, it is called an *excisional biopsy*. These procedures are often able to be done with just local anesthesia (numbing medicine).

Chest x-ray

The lungs may be x-rayed to see if KS is there. If the x-ray shows something abnormal, other tests will be needed to tell for sure if it is KS or some other condition. If someone is known to have KS in the lung, chest x-rays can be used to see how the disease is responding to treatment.

Bronchoscopy

This procedure lets the doctor look into the lungs. It is often done if the patient is having problems such as shortness of breath or coughing up blood, or if the chest x-ray shows something abnormal. Any of these could mean that KS is in the lungs. Before starting the bronchoscopy, the patient is put to sleep with a light anesthesia. Then the doctor inserts the bronchoscope (a thin, flexible lighted tube) through the mouth, down the windpipe, and into the lungs. If the doctor sees a KS lesion, it can be biopsied through the bronchoscope. Bronchoscopy with biopsies can also be used to help diagnose other lung problems seen in AIDS patients, such as pneumonia.

Gastrointestinal endoscopy

This is done when the doctor suspects that KS is in the stomach or intestines and is causing problems.

Three types of endoscopy are used to look at the stomach and intestines.

- **Upper endoscopy** (also called *esophagoduodenoscopy*, or *EGD*) is used to examine the esophagus, the stomach, and the first part of the small intestine. For this procedure, the patient is first given medicines to make them sleepy. Then, the doctor guides the endoscope (a thin, flexible, lighted tube) through the mouth and esophagus and into the stomach. This allows the doctor to see things like ulcers, infections, and KS lesions. If a lesion is seen, the doctor can use small surgical instruments through the endoscope to biopsy it.
- **Colonoscopy** is used to look inside the large intestine (colon). Before this test can be done, the colon must be cleaned out to remove any stool. This often means drinking a

large amount of a liquid laxative the night before and the morning of the procedure. Sometimes enemas are used as well. Just before the procedure, the patient is given medicine into a vein to make him or her sleepy. Then a colonoscope (a long, flexible, tube with a light or camera on the end) is inserted through the rectum and into the colon. Any lesion seen can be biopsied.

- **Capsule endoscopy** is a way to look at the small intestine. It is not truly a type of endoscopy, since it doesn't use an endoscope. Instead, this procedure uses a capsule (about the size of a large vitamin pill) that contains a light source and a very small camera. The patient swallows the capsule. Like any other pill, the capsule goes through the stomach and into the small intestine. As it travels through the small intestine (usually over the course of about 8 hours), it takes thousands of pictures. These images are transmitted electronically to a device worn around the person's waist while he or she goes on with normal daily activities. The pictures can then be downloaded onto a computer, where the doctor can look at them as a video. The capsule passes out of the body during a normal bowel movement and is flushed away.
- **Double balloon enteroscopy** is another way to look at the small intestine. Regular endoscopy cannot look very far into the small intestine because it is too long (20 feet) and has too many curves. This method gets around these problems by using a special endoscope that is made up of 2 tubes, one inside the other. First the inner tube, which is an endoscope, goes forward about a foot, and then a balloon at its end is inflated to anchor it. Then the outer tube goes forward to near the end of the inner tube and it is then anchored in place with a balloon. This process keeps being repeated over and over, letting the doctor see the intestine a foot at a time. The doctor can even take a biopsy if something abnormal is seen. This procedure is done after the patient is given drugs to make him or her sleepy. This procedure is more involved than capsule endoscopy, but it has the advantage of allowing the doctor to biopsy any lesions seen.

KS can also affect other organs, such as the liver, spleen, heart, or bone marrow. These areas do not often need to be biopsied if the patient is already known to have KS based on biopsies of other tissues, such as skin, lungs, or intestines.

How is Kaposi sarcoma staged?

Staging is the process of using physical exams, imaging tests, and, in some cases, biopsy results to determine where and how much cancer is in the body. For many types of cancer, the stage is the most important factor in selecting treatment options and predicting a patient's outlook for recovery and survival. The results of the staging process are usually described in a standardized way, using a *staging system*.

There is no officially accepted system for staging all types of Kaposi sarcoma (KS) like there is for most other forms of cancer. But most doctors now use the AIDS Clinical Trials Group system.

Staging systems for most other types of cancer are based mostly on the size of the primary lesion (the first one to develop) and how far the cancer has spread from that lesion. But the outlook for patients with AIDS-related KS is influenced at least as much

by the presence of other AIDS-related problems as it is by the spread of KS. For this reason, staging of KS also considers factors such as how much the immune system is damaged and the presence of AIDS-related infections.

The AIDS Clinical Trial Group system

In 1988 a group of researchers known as the AIDS Clinical Trials Group (ACTG) proposed a staging classification system for AIDS-related Kaposi sarcoma. The ACTG system considers 3 factors:

- The extent of the tumor (abbreviated T)
- The status of the immune system (I), as measured by the number of certain cells (CD4 cells) present in the blood
- The extent of involvement within the body or systemic illness (S)

Under each of these major headings, there are 2 subgroups identified by either a zero (0, or good risk) or a 1 (poor risk). The following are the possible staging categories under this system:

T (tumor) status

T0 (good risk): Localized tumor

KS is only in the skin and/or the lymph nodes, and/or there is only a small amount of disease on the palate (roof of the mouth). The KS lesions in the mouth are flat rather than raised

T1 (poor risk): The KS lesions are widespread. One or more of the following is present:

- Edema (swelling) due to the tumor
- Extensive oral KS: lesions that are nodular (raised) and/or lesions in areas of the mouth besides the palate (roof of the mouth)
- Lesions of KS are in organs other than lymph nodes (such as the lungs, the intestine, the liver, etc.). Kaposi sarcoma in the lungs is a particularly bad sign.

I (immune system) status

I0 (good risk): CD4 cell count is 200 or more cells per cubic mm (the normal range is 600–1500 per cubic mm). More recent studies have used counts of either 150 or 100.

I1 (poor risk): CD4 cell count is lower than 200 cells per cubic mm. More recent studies have used counts of either 150 or 100.

S (systemic illness) status

S0 (good risk): No systemic illness present; all of the following are true:

No history of opportunistic infections or thrush (thrush is a fungal infection in the mouth, opportunistic infections are infections that rarely cause problems in healthy people, but more commonly affect people with suppressed immune systems).

No *B symptoms* are present. B symptoms include:

- Unexplained fever
- Night sweats (severe enough to soak the bed clothes)
- Weight loss of more than 10% without dieting
- Diarrhea persisting more than 2 weeks

And this is true:

- Karnofsky performance status score of 70 or higher. (This means you are up and about most of the time and able to take care of yourself.)

S1 (poor risk): Systemic illness present; one or more of the following is true:

- History of opportunistic infections or thrush
- One or more *B symptoms* is present
- Performance status score under 70
- Other HIV-related illness is present, such as neurological (nervous system) disease or lymphoma

Survival of patients with Kaposi sarcoma

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 read them, 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.

Five-year *relative* survival rates assume that some people will die of other causes and compare the observed survival with that expected for people without the cancer. This is a better way to see the impact of the 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 Kaposi 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 affect a person's outlook, such as their age and general health, how well

their immune system functions, and their response to HAART. Your doctor can tell you how the numbers below apply to you, as he or she is familiar with the aspects of your particular situation.

Research has shown that people who are at good risk in any of the AIDS Clinical Trials Group (ACTG) categories live longer than those who are not. As treatment of the HIV infection continues to improve, so does the outlook of Kaposi sarcoma (KS). It takes time to see the effect of the most up to date treatment on survival rates, since they are based on patients first diagnosed years ago. At one point during the AIDS epidemic, the outlook for patients with KS was grim, with less than 10% of patients surviving at least 5 years after diagnosis. This has improved over time, with the most recent data, from the National Cancer Institute's SEER program showing an overall 5-year relative survival of about 67%. The cause of death for people with KS is not always the KS. Often, people with KS die from diseases related to HIV and AIDS, and not the KS itself.

When looking at patients staged by the ACTG staging system, those at good risk T and I factors combined, have a 5-year survival of 90%. For those at poor risk in these categories, the 5-year survival was around 50%. It dropped to 30% if the KS were in the lungs.

How is Kaposi 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.

General treatment information

Treatment for Kaposi sarcoma (KS) is more effective than it was a couple of decades ago. Doctors now better understand what causes KS. Many clinical trials have compared different approaches to treatment. Doctors have much more experience with KS than they did when this disease was quite rare. Choices about the best treatment options for each patient are based on the function of the immune system as well as the number, location and size of the KS lesions. The patient's general condition is also a major factor. The presence and severity of other serious medical conditions can make some treatments a poor choice. Some of the treatments used for KS are surgery, chemotherapy, radiation therapy, and biologic therapy. In some cases, 2 or more of these treatments are used together.

Treating immune deficiency and related infections for Kaposi sarcoma

The most important treatment for Kaposi sarcoma (KS) is treating any immune deficiency that exists as well as any related infections. In people with AIDS, this means using combinations of anti-HIV drugs. This is known as *highly active antiretroviral therapy* (HAART). For many AIDS patients, HAART may be the only treatment needed for the KS. In organ-transplant patients who are immune-suppressed because they are taking medicines, decreasing or changing the drugs may be helpful. New KS lesions are more likely to develop when a patient's blood test results for KS herpesvirus (KSHV) are positive. The risk of developing new lesions is lower when antiviral medicines such as ganciclovir or foscarnet are used. These medicines may help prevent new lesions but do not help existing lesions get better. KS lesions tend to get worse when patients develop infections with bacteria. Therefore, it is very important to take measures to prevent bacterial infections and to treat them promptly and effectively if they do occur.

Local therapy for Kaposi sarcoma

Local treatment is a type of treatment that only affects certain Kaposi sarcoma (KS) lesions (or areas of lesions). This type of treatment is often used to treat a few skin lesions in one spot to help the patient look or feel better. It is most useful when there are just a few lesions that are in a very visible area (such as the face). The drawback of local therapy is that it doesn't treat lesions elsewhere and it can't keep new lesions from developing.

One form of local therapy is called *topical treatment*. This puts the medicine directly on the lesion. Alitretinoin, a substance related to vitamin A, is available as a gel (Panretin[®]) that can be used to treat KS skin lesions. When it is placed on a KS lesion 2 to 4 times a day, it causes it to get smaller or go away in 1 to 2 months. Side effects of this gel include skin irritation and lightening of the skin.

Another type of local treatment is cryosurgery. In this procedure a probe cooled with liquid nitrogen is used to freeze the lesions. This has a good success rate.

Another approach is called *intralesional chemotherapy*. A small amount of a chemotherapy drug is injected directly into the KS lesions. Only a small amount of the drug is needed and very little is absorbed into the body. This lets the patient avoid many of the side effects normally seen with chemotherapy. The most common drug used for intralesional chemotherapy in KS is called vinblastine. In the past, an immune-stimulating drug called interferon was used for these injections, but it is rarely used now. Sodium tetradecyl sulfate (STS or Sotradecol[®]) is another drug used for intralesional chemotherapy of KS.

Photodynamic treatment is also an option. The patient is given a drug that builds up more in tumor cells than in normal skin. About 48 hours after giving the drug, light is used to activate the drug, which kills the cells.

Radiation therapy for Kaposi sarcoma

Radiation therapy uses high-energy radiation to kill cancer cells. When the radiation is delivered from outside the body it is called *external beam radiation therapy*. This is the type of radiation therapy most often used to treat lesions of Kaposi sarcoma (KS).

Radiation therapy is often used as a local therapy to treat KS when the disease is only in a few areas. Radiation treatments are used to reduce symptoms like pain or swelling. It is also used for skin lesions that look bad and are in places that can easily be seen (like the face). The form of radiation often used to treat the skin is called *electron-beam radiation therapy (EBRT)*. It uses tiny particles called *electrons* that don't penetrate far past the skin's surface. This lessens non-skin side effects. EBRT can also be used to treat a large area if the patient has many, widespread KS lesions.

Radiation can also be used to treat KS lesions in the mouth or throat. The form of radiation used for this is known as *photon radiation*.

Side effects of radiation therapy can include skin changes, nausea, vomiting, and fatigue. Radiation can also cause anemia (low red blood cells), as well as lower numbers of white blood cells, which increases the risk of infection. Serious side effects are rare when radiation is given to just a small area of the skin, but about 5% of patients will have severe skin reactions. When radiation is used to treat KS lesions in the mouth or throat, these areas can become painful and open sores can develop. If chemotherapy and radiation are given at the same time, the side effects are worse. For more information on radiation therapy, see our document, *Understanding Radiation Therapy: A Guide for Patients and Families*.

Surgery for Kaposi sarcoma

When only a few, small Kaposi sarcoma lesions are present, they may be removed with surgery.

Chemotherapy for Kaposi sarcoma

Chemotherapy (chemo) is the use of drugs to treat cancer. When the drugs are given into a vein or by mouth, they enter the bloodstream to reach all areas of the body. This is a type of *systemic treatment*. It is useful to treat cancer that has spread to many areas of the body. When the drugs are injected directly into a tumor it is called *intralesional chemotherapy* (see the section, "Local therapy," above).

For systemic chemo the drugs used most often to treat Kaposi sarcoma (KS) belong to a group known as *liposomal anthracyclines*. Anthracyclines are drugs that treat many different cancers, such as lymphoma and breast cancer. In liposomal anthracyclines, the drugs are enclosed in tiny fat globules. In this form, they are better taken up by tumors and have fewer side effects. They have become the first choice for KS treatment. The 2 liposomal anthracyclines used in the US to treat KS are doxorubicin (Doxil[®]) and daunorubicin (DaunoXome[®]).

Other chemotherapy drugs that treat KS are paclitaxel (Taxol[®]), gemcitabine (Gemzar[®]) and vinorelbine (Navelbine[®]). Drugs used in the past include bleomycin, vinblastine (Velban[®]), vincristine (Oncovin[®]), and etoposide (VP-16).

More than half of KS patients treated with chemotherapy will improve, but KS generally doesn't go completely away. It is sometimes possible to stop treating the KS as long as lesions are not causing problems or increasing in size and number. If there is evidence that the KS is starting to get worse, treatment can resume. In all patients, it is important to try to improve immune function and treat related infections. This is especially important when giving chemotherapy, which generally decreases the body's ability to fight some infections.

Chemotherapy drugs kill cancer cells but also can damage some normal cells. This happens more often when they are given as a systemic treatment. Your health care team will pay careful attention to avoiding or minimizing side effects. The side effects you experience depend on the type of drugs, the amount taken, and the length of treatment. Common temporary side effects might include:

- Nausea and vomiting
- Loss of appetite
- Loss of hair
- Mouth sores
- Low blood counts

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

- An increased risk 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)

Drugs such as vincristine or paclitaxel can damage nerves (called *neuropathy*), sometimes leading to feelings of numbness, particularly in your fingers and toes. This damage can also cause some weakness in your arms and legs. These problems tend to be worse in AIDS patients because the AIDS virus affects bone marrow and often nerve cells.

Some side effects disappear a few days after treatment, but some can last a long time (or even be permanent). Be sure to ask your doctor about the possible side effects from chemotherapy drugs that you will receive. There are good treatments to prevent or reduce many of the temporary side effects of chemotherapy. For example, your doctor can prescribe anti-nausea drugs for you to prevent or reduce nausea and vomiting.

For more information on chemotherapy, see our document, *Understanding Chemotherapy: A Guide for Patients and Families*.

Biologic therapy for Kaposi sarcoma

Biologic therapy uses chemicals produced naturally by the body (or forms of these chemicals manufactured in a lab) to help the immune system attack cancer cells. One of the first drugs used to treat Kaposi sarcoma (KS), interferon alfa, is an example of biologic therapy. For KS, interferon is injected daily. The injection can be directly into a muscle (called *IM*) or under the skin (called *sub-q*). Interferon seems to work by preventing viruses from reproducing and by activating immune system cells that attack and destroy the virus.

Between 25% and 50% of patients with good immunologic function improve when given high doses of these drugs, but patients with fevers, weight loss, or low CD4 counts rarely respond to interferon. The best success rates occur in patients who do not have opportunistic infections and those who have a relatively healthy immune system. It can take 6 months or more to see a response from this treatment.

The most common side effects of interferon therapy are flu-like symptoms (fever, pain, and weakness). Treatment with interferon can also cause low blood counts, liver problems, and confusion. It can take months of treatment with interferon before the KS lesions show improvement. Interferon alfa was one of the first treatments for AIDS-related KS, but it is not often used now because of its side effects and because it doesn't work well in many patients with AIDS.

More information on biologic therapy can be found in our document, *Immunotherapy*.

Clinical trials for Kaposi sarcoma

You may have had to make a lot of decisions since you've been told you have cancer. One of the most important decisions you will make is choosing which treatment is best for you. You may have heard about clinical trials being done for your type of cancer. Or maybe someone on your health care team has mentioned a clinical trial to you.

Clinical trials are carefully controlled research studies that are done with patients who volunteer for them. They are done to get a closer look at promising new treatments or procedures.

If you would like to take part in a clinical trial, you should start by asking your doctor if your clinic or hospital conducts clinical trials. You can also call our clinical trials matching service for a list of clinical trials that meet your medical needs. You can reach this service at 1-800-303-5691 or on our Web site at 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 Web site at www.cancer.gov.

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

Clinical trials are one way to get state-of-the-art cancer treatment. They are the only way for doctors to learn better methods to treat cancer. Still, they are not right for everyone.

You can get a lot more information on clinical trials in our document called *Clinical Trials: What You Need to Know*. You can read it on our Web site or call our toll-free number (1-800-227-2345) and have it sent to you.

Complementary and alternative therapies for Kaposi sarcoma

When you have cancer you are likely to hear about ways to treat your cancer or relieve symptoms that your doctor hasn't mentioned. Everyone from friends and family to Internet groups and Web sites 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 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.

General considerations in the treatment of Kaposi sarcoma

Different treatment options for Kaposi sarcoma (KS) were discussed in the previous section, "How is Kaposi sarcoma treated." Deciding which treatment to use depends on a number of factors, such as

- The type of KS (which helps predict how fast the disease may grow and spread)
- The number of lesions
- What kinds of problems the KS is causing
- The patient's health

These factors need to be considered because certain treatments, such as chemotherapy, can have serious side effects. Someone who is weak or sick from other problems may not be able to tolerate chemotherapy. In a case like this, the chemo may do more harm than good.

AIDS-related Kaposi sarcoma

For someone with AIDS, the most important part of KS treatment is to fight the HIV infection with modern anti-AIDS drug combinations. For many patients, KS lesions begin to get smaller as their immune function gets better. In some patients with AIDS, highly active antiretroviral therapy (HAART) may be the only treatment needed to treat the KS. HAART also helps AIDS patients live longer and feel better. Still, other treatments for KS may be needed to improve symptoms (like pain and swelling).

A local treatment may be used for a few skin or mouth lesions. KS tumors of the skin, mouth, or anus are sometimes treated with low-doses of radiation therapy. As a rule, doctors use radiation therapy to relieve symptoms or treat highly visible lesions. Sometimes radiation is given to patients who can't have chemotherapy because they are too weak or have poor liver function.

Chemotherapy may be added to HAART for patients with:

- Many skin or mouth lesions
- Severe swelling from KS (*lymphedema*)
- Lung lesions causing shortness of breath
- Lesions in the stomach and intestines that have caused anemia (low red blood cell count), weight loss, or other problems

For chemotherapy, paclitaxel or one of the liposomal anthracyclines is usually chosen. If those drugs do not work, other chemotherapy drugs can be tried (see the section, "Chemotherapy").

Classic Kaposi sarcoma

Classic KS grows and spreads slowly, so lesions are more often treated with surgery or one of the local treatments. Chemotherapy may be used for widespread skin lesions or advanced KS. KS is considered advanced if it has spread to the lymph nodes or affects the lungs or gastrointestinal tract. Liposomal anthracyclines or paclitaxel are the drugs most often used for chemotherapy. Radiation therapy is also an option for individual lesions or groups of lesions.

Transplant-related Kaposi sarcoma

Sometimes lesions disappear on their own if the drugs that suppress the immune system are changed or stopped. A drug called *sirolimus* may be used in place of another anti-rejection drug because it can make Kaposi lesions get smaller. Skin lesions can be treated with radiation therapy or a local treatment. Most doctors try to avoid giving people who have had organ transplants chemotherapy for KS. But some patients may agree to participate in clinical trials of new drugs.

Endemic Kaposi sarcoma

Because endemic KS occurs in poor countries, treatment options are often limited. When available, the same treatments given for classic KS may be used.

Kaposi sarcoma in HIV-negative men having sex with men

This form of the disease is similar to classic KS, only it occurs in younger men. It is treated like classic KS.

More treatment information

For more details on treatment options — including some that may not be addressed in this document — the National Cancer Institute (NCI) may be a good source of information.

What should you ask your doctor about Kaposi sarcoma?

As you cope with Kaposi sarcoma (KS) and its treatment, you need to have honest, open discussions with your doctor. You should feel free to ask any question that's on your mind no matter how small it might seem. Here are some questions you might want to ask. Keep in mind that nurses, social workers, and other members of the treatment team might also be able to answer many of your questions.

- What is the stage of my KS? What does the staging mean in my case?
- What is my CD4 count and should I be doing anything to try to increase it?
- Are there any other infections contributing to my condition?
- For HIV-associated KS, is my HIV viral load controlled?
- What treatment choices do I have?
- Based on what you've learned about my cancer, what is my prognosis (outlook)?
- What side effects can I expect from my treatment?
- What are the other risks of treatment?
- How long will it take me to recover from treatment?
- When can I go back to work after treatment?
- What should I do to be ready for treatment?
- Should I get a second opinion?
- Is there a support group in my town for patients in my situation?

You will no doubt have other questions about your own personal situation. Be sure and write your questions down so you remember to ask them during each visit with your cancer care team.

What happens after treatment for Kaposi sarcoma?

For some people with Kaposi sarcoma, treatment may completely remove or destroy the cancer. 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 real concern for those who have Kaposi sarcoma (KS), since treatments are rarely expected to cure the disease completely.

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 leading full lives. Our document, *Living With Uncertainty: The Fear of Cancer Recurrence*, gives more detailed information on this.

For many people with Kaposi sarcoma, the cancer never goes 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*, covers more about this.

Follow-up care

Even if your 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.

After your cancer treatment is finished, you will probably need to still see your cancer doctor for many years. So, ask what kind of follow-up schedule you can expect.

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. 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 were in the hospital, a copy of the discharge summary that doctors prepare when patients are sent home
- If you were treated with radiation, a copy of the treatment summary
- If you had drug treatment (including chemotherapy, antiviral drugs, and biologic therapy), a list of the drugs, drug doses, and when you took them

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

Lifestyle changes

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 may 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 put healthy eating habits into place. 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. 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 twice a week. If you haven't exercised 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 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, 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*.)

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 about 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 stops working

It is important to be aware that there is no cure for Kaposi sarcoma (KS) and that treatment for KS does not appear to prolong life. There is always a chance that lesions may return, either at the original site or in other places on the skin or internal organs. Advanced KS usually means advanced AIDS, with all its problems. Still, treatment for KS is very effective at taking care of the symptoms of the disease. It can shrink or get rid of bulky, painful, and tender lesions and can relieve swelling. It also reduces problems that arise when tumors affect the lungs or gastrointestinal tract. By reducing suffering and improving cosmetic appearance, treatment for KS brings about important improvements in the quality of life.

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 a 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 Kaposi sarcoma research and treatment?

A great deal of research is being done to find more effective treatments for Kaposi sarcoma (KS). Angiogenesis inhibitors are drugs that block the development of blood vessels within tumors. Since blood vessels are the main component of KS lesions, this approach to treatment seems promising. One problem, however, is they are associated with side effects such as high blood pressure and bleeding.

In one study, the angiogenesis inhibitor, bevacizumab (Avastin), was injected into a vein (IV) to treat KS. This drug is also being studied as intralesional therapy for KS (injected directly into the KS lesions).

The immunotherapy drug interleukin-12 (IL-12) showed good results in a small study of 24 patients. In another study it was given first along with the chemo drug liposomal doxorubicin, and then given as maintenance treatment for up to 3 years. This treatment worked well to shrink tumors and keep them from growing back. Other ways of giving this drug are being studied.

New combinations of current chemotherapy drugs and combinations of chemotherapy with antiretroviral drugs are all being tested in clinical trials. Of course, research into HIV vaccines and antiretroviral drugs also may have a great impact on AIDS-related KS. Human herpesvirus-8 (HHV-8) also offers a new target for KS drugs and biologic therapy. Clinical trials are testing whether antiviral drugs that target HHV-8 may be used for KS.

Perhaps the most important advance in the treatment of AIDS-related KS is the development of effective treatment for AIDS. This has reduced the chance of getting KS and in many cases reduced the KS lesions themselves.

Testing for Kaposi sarcoma herpesvirus (KSHV), the virus that causes KS, could help manage patients at risk for KS, including those infected with HIV or those who will be having an organ transplant and will be on immunosuppressive drugs. Several drugs used to treat related herpesviruses such as cytomegalovirus are also effective for KSHV infections. These drugs seem to reduce the development of KS in patients at risk even though these drugs are generally not effective at treating KS once it has developed. These drugs stop the KSHV-infected cells from producing more of the virus.

Additional resources for Kaposi sarcoma

More information from your American Cancer Society

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

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

HIV/AIDS (also available in Spanish)

Immunotherapy

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

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

Books

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

Caregiving: A Step-By-Step Resource for Caring for the Person With Cancer at Home

National organizations and Web sites*

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

AIDSinfo

Toll-free number: 1-800-448-0440

Web site: www.aidsinfo.nih.gov

CDC National Prevention Information Network (CDC NPIN)

Toll-free number: 1-800-458-5231

Web site: www.cdcnpin.org

National Cancer Institute

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

TTY: 1-800-332-8615

Web site: www.cancer.gov

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

No matter who you are, we can help. Contact us any time, day or night, for information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

References: Kaposi sarcoma detailed guide

Ambiner RF, Wagner-Johnston ND. HIV-associated malignancies. In: Abeloff MD, Armitage JO, Lichter AS, Niederhuber JE, Kastan MB, McKenna WG. *Clinical Oncology*. Philadelphia, PA: Elsevier; 2008: 1061–1071.

Brown EE, Whitby D, Vitale F, et al. Virologic, hematologic, and immunologic risk factors for classic Kaposi sarcoma. *Cancer*. 2006 Nov 1;107:2282–2290.

- Di Lorenzo G, Konstantinopoulos PA, Pantanowitz L, et al. Management of AIDS-related Kaposi's sarcoma. *Lancet Oncol*. 2007;8:167–176.
- Eltom MA, Jemal A, Mbulaiteye SM, et al. Trends in Kaposi's sarcoma and non-Hodgkin's lymphoma incidence in the United States from 1973-1998. *J Natl Cancer Inst*. 2002;94: 1204–1210.
- Engels EA, Atkinson JO, Graubard BI, et al. Risk factors for human herpesvirus 8 infection among adults in the United States and evidence for sexual transmission. *J Infect Dis*. 2007 Jul 15;196(2):199–207. Epub 2007 Jun 4.
- Geraminejad P, Memar O, Aronson I, et al. Kaposi's sarcoma and other manifestations of human herpesvirus 8. *J Am Acad Dermatol*. 2002;47:641–655.
- Howlader N, Noone AM, Krapcho et al (eds). SEER Cancer Statistics Review, 1975-2008, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2008/, based on November 2010 SEER data submission, posted to the SEER web site, 2011
- Iscovich J, Boffetta P, Franceschi S, Azizi E, Sarid R. Classic Kaposi sarcoma: epidemiology and risk factors. *Cancer*. 2000;88:500–517.
- Krown SE, Testa MA, Huang J. AIDS-related Kaposi's sarcoma: prospective validation of the AIDS Clinical Trials Group staging classification. AIDS Clinical Trials Group Oncology Committee. *J Clin Oncol*. 1997;15:3085–3092.
- Lanternier F, Lebbé C, Schartz N, et al. Kaposi's sarcoma in HIV-negative men having sex with men. *AIDS*. 2008;22:1163–1168.
- Little RF, Aleman K, Kumar P, et al. Phase 2 study of pegylated liposomal doxorubicin in combination with interleukin-12 for AIDS-related Kaposi sarcoma. *Blood*. 2007 Dec 15;110(13):4165–4171. Epub 2007 Sep 10.
- Lodi S, Guiguet M, Costagliola D, Fisher M, de Luca A, Porter K; CASCADE Collaboration. Kaposi sarcoma incidence and survival among HIV-infected homosexual men after HIV seroconversion. *J Natl Cancer Inst*. 2010 Jun 2;102(11):784–792. Epub 2010 May 4.
- Mocroft A, Kirk O, Clumeck N. The changing pattern of Kaposi sarcoma in patients with HIV, 1994-2004. *Cancer*. 2004;100:2644–2654.
- Nasti G, Talamini R, Antinori A, et al. AIDS-related Kaposi's Sarcoma: evaluation of potential new prognostic factors and assessment of the AIDS Clinical Trial Group Staging System in the Haart Era--the Italian Cooperative Group on AIDS and Tumors and the Italian Cohort of Patients Naive From Antiretrovirals. *J Clin Oncol*. 2003;21:2876–2882.
- Physician data query (PDQ) summary: Kaposi sarcoma treatment. 4/4/2011. National Cancer Institute. Accessed at <http://www.cancer.gov/cancertopics/pdq/treatment/kaposi/healthprofessional> on September 12, 2011.

Scadden DT. Neoplasms in Acquired Immunodeficiency Syndrome. In: Kufe DW, Pollock RE, Weichselbaum RR, Bast RC, Gansler TS, Holland JF, Frei E. *Cancer Medicine* 6. Hamilton, Ontario: BC Decker; 2003: 2259–2276.

Serraino D, De Paoli A, Zucchetto A, Pennazza S, Bruzzone S, Spina M, De Paoli P, Rezza G, Dal Maso L, Suligo B. The impact of Kaposi sarcoma and non-Hodgkin lymphoma on mortality of people with AIDS in the highly active antiretroviral therapies era. *Cancer Epidemiol.* 2010 Jun;34(3):257–261. Epub 2010 Apr 22.

Strother RM, Gregory KM, Pastakia SD, et al. Retrospective analysis of the efficacy of gemcitabine for previously treated AIDS-associated Kaposi's sarcoma in western Kenya. *Oncology.* 2010;78(1):5–11. Epub 2010 Mar 6.

Yarchoan R, Little RF. Acquired Immunodeficiency Syndrome-Related malignancies. In: DeVita VT Jr, Hellman S, Rosenberg SA. *Cancer: Principles & Practice of Oncology.* 8th ed. Philadelphia: Lippincott Williams & Wilkins; 2008: 2401–2417.

Last Medical Review: 10/26/2011

Last Revised: 1/24/2012

2011 Copyright American Cancer Society

For additional assistance please contact your American Cancer Society
1 · 800 · ACS-2345 or www.cancer.org