Kaposi 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 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 still 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. It usually appears as tumors on the skin or on mucosal surfaces such as inside the mouth, but tumors can also develop in other parts of the body, such as in the lymph nodes (bean-sized collections of immune cells throughout the body) or digestive tract.

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 most often appear on the legs or face. They may look bad, but they usually cause no symptoms. Some lesions on the legs or in the groin area may cause the legs and feet to swell painfully.

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 trouble breathing.

Types of Kaposi sarcoma

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, often 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 or 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.

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).

In the United States, treating 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. 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.

Classic (Mediterranean) Kaposi sarcoma

Classic KS occurs mainly in older 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 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, so the risk of KS is higher. Other factors in Africa also probably 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 progress quickly.

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 more common.

Iatrogenic (transplant-related) Kaposi sarcoma

When KS develops in people whose immune systems have been suppressed after an organ transplant, it is called *iatrogenic*, or *transplant-related KS*. Most transplant patients

need to take drugs to keep their immune system from rejecting (attacking) the new organ. But 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 go away 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) was rare in the United States. At that time, only about 2 new cases of KS were found for every million people in the United States each year. Most often, the types of KS that occurred were classic and transplant-related.

With the AIDS epidemic, the rate of KS in this country increased more than 20 times — peaking at about 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 6 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.

Transplant recipients are another group that gets KS. About 1 in 200 transplant patients in the United States gets KS. Most of these people were already infected with Kaposi sarcoma herpesvirus (KSHV) before the transplant, but the virus didn't cause problems because their immune system kept it in check. The drugs these people take to suppress their immune system allow KS to develop.

In areas of the world (such as Africa) where KSHV and HIV infection rates are high, both endemic and HIV-associated KS are seen, and KS occurs in men, women, and children.

Do we know what causes Kaposi sarcoma?

Kaposi sarcoma (KS) is caused by infection with a virus called the *Kaposi sarcoma herpesvirus* (KSHV), also known as *human herpesvirus 8* (HHV8). KSHV is similar to Epstein-Barr virus (EBV), the virus that causes infectious mononucleosis (mono) and is linked to several types of cancer.

In KS, the cells that line blood and lymphatic vessels (called *endothelial cells*) are infected with KSHV. The virus brings genes into the cells that can cause the cells to divide too much and to live longer than they should. These types of changes may eventually turn them into cancer cells.

KSHV infection is much more common than KS, and most people infected with this virus do not get KS. Many people infected with KSHV will never show any symptoms. Infection with KSHV seems to be needed to cause KS, but in most cases infection with KSHV alone does not lead to KS. Most people who develop KS also have a weakened immune system, due to HIV infection, organ transplant, older age, or some other factor.

The percentage of people infected with KSHV varies 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. 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 also found in saliva, which may be one of the ways it is passed to others.

For more on infections and their role in cancer, see our document *Infectious Agents and Cancer*.

Can Kaposi sarcoma be prevented?

Kaposi sarcoma (KS) is caused by the Kaposi sarcoma herpesvirus (KSHV). There are no vaccines at this time 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. Many people with HIV don’t know that they are infected, so 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.

- HIV can also be spread through the use of contaminated (dirty) needles to inject recreational drugs. For people who inject drugs, the safest way to avoid HIV is to quit. However, some people are unable to quit on their own or get help in quitting, and they may not be able to stop using drugs right away. For these people, clean needles and injection supplies can help protect them. In some areas, there are programs to make sure that drug users can get clean needles and syringes.

- HIV-infected mothers can pass the virus to their babies during pregnancy, delivery, or breastfeeding. Treating the mothers and infants with anti-HIV drugs and avoiding breastfeeding can greatly reduce the risk of these infections.
- In the past, blood product transfusions and organ transplants were responsible for some HIV infections. As a result of improved testing for HIV, there is now a very low risk of HIV infection from blood products or organ transplants in the United States.

For people who are infected with HIV and KSHV, taking the right medicines can reduce the chance of developing KS.

- Testing for HIV can identify people 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 that people with HIV will develop KS (and AIDS). Treating infections that commonly occur in people with weakened immunity also reduces the likelihood of developing problems with KS.
- HIV-infected people who take drugs to treat herpesvirus infections (such as ganciclovir or foscarnet) are less likely to develop KS because these drugs also work against KSHV (which is a type of herpesvirus). Still, these drugs can have serious side effects, so 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 different, because it tends to form in several areas at the same time. Even when only one skin lesion is visible, many people already have other areas of KS that are just too small to be seen.

There are no recommended routine screening tests to look for KS in people who are not at increased risk of the disease.

People infected with HIV are much more likely to develop KS, so many health experts recommend that people infected with HIV be examined regularly by health care providers who are experienced in recognizing KS and other diseases that go along with HIV infection and AIDS. People with possible symptoms of KS (see “How is Kaposi sarcoma diagnosed?”) should see their doctors right away so that the cause can be found as soon as possible and treated, if needed.

How is Kaposi sarcoma diagnosed?

Kaposi sarcoma (KS) is often found when a person goes to the doctor because of signs or symptoms they are having. Sometimes KS may be found during a routine physical exam. If KS is suspected, further tests will be needed to confirm the diagnosis.

Signs and symptoms of Kaposi sarcoma

KS usually appears first on the skin, forming purple, red, or brown patches (not raised above the surrounding skin), plaques (flat areas that are slightly raised), or nodules (bumps) that are called *lesions*. The skin lesions of KS most often develop on the legs or face, but they can also appear in other areas. Lesions can also develop on mucous membranes such as those inside the mouth. The lesions are usually not painful or itchy. Some lesions on the legs or in the groin area might block the flow of fluid out of the legs. This can lead to painful swelling in the legs and feet.

KS lesions can also sometimes appear in other parts of the body. Lesions in the lungs might block part of an airway and cause shortness of breath. Lesions that develop in the intestines can cause abdominal pain, diarrhea, or bleeding from the rectum.

Medical history and physical exam

If your doctor suspects you might have KS, you will be asked about your medical history to learn about illnesses, operations, your sexual activity, and other possible exposures to Kaposi sarcoma herpesvirus (KSHV) and HIV. The doctor will ask you about your symptoms and about any skin tumors you have noticed.

As part of a complete physical exam, the doctor will examine your skin and the inside of your mouth to look for KS lesions. Sometimes KS lesions develop inside the rectum (the part of the large intestine just inside the anus). A doctor might be able to feel these 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*. A specially trained doctor called a *pathologist* can often diagnose KS by looking at the cells in the biopsy sample under a microscope.

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 can often be done with just local anesthesia (numbing medicine).

Lesions in other areas, such as the lungs or intestines, can be biopsied during other procedures such as bronchoscopy or endoscopy, which are described below.

Chest x-ray

The lungs may be x-rayed to see if KS is there. If the x-ray shows something abnormal, other tests might 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

Bronchoscopy lets the doctor look into the windpipe (trachea) and the large airways of the lungs. This procedure 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 with a small video camera on the end) through the mouth, down the windpipe, and into the lungs. If the doctor sees an abnormal area that might be KS, 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

One or more of these tests might be done when the doctor suspects that KS is in the stomach or intestines and is causing problems.

- **Upper endoscopy** (also called *esophagogastroduodenoscopy*, or *EGD*) is used to look at the inner lining of the esophagus, the stomach, and the first part of the small intestine. For this procedure, the patient is first given drugs to make them sleepy. Then, the doctor guides the endoscope (a thin, flexible, lighted tube with a small video camera on the end) through the mouth and esophagus and into the stomach and small intestine. This lets the doctor see things like ulcers, infections, and KS lesions. If an abnormal area 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 and rectum). Before this test can be done, the colon and rectum 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 intravenous (IV) medicine to make him or her relaxed or even asleep. Then a colonoscope (a long, flexible, tube with a light and video camera on the end) is inserted through the rectum and into the colon. Any abnormal areas 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, the patient swallows a capsule (about the size of a large vitamin pill) that contains a light source and a very small camera. Like any other pill, the capsule goes through the stomach and into the small intestine. As it travels through the small intestine (usually over 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

images 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 discarded. A disadvantage of this test is that it doesn't allow the doctor to biopsy any abnormal areas.

- **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 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. The patient is given intravenous (IV) medicine to make him or her relaxed, or even asleep. The endoscope is then inserted either through the mouth or the anus, depending on if there is a specific part of the small intestine to be examined. Once inside the small intestine, the inner tube, which has the camera on the end, is advanced about a foot as the doctor looks at the lining of the intestine. Then a balloon at its end is inflated to anchor it. The outer tube is then pushed forward to near the end of the inner tube and is anchored in place with a second balloon. This process is 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 more involved than capsule endoscopy (and may take as long as 2 hours to complete), but it has the advantage of letting the doctor 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?

For many types of cancer, the stage is a description of how far the cancer has spread, based on the results of physical exams, biopsies, and imaging or other tests (see "How is Kaposi sarcoma diagnosed?"). The stage of a cancer is often one of the most important factors in selecting treatment options and predicting a patient's survival outlook.

The results of the staging process are usually described in a standard way, using a *staging system*. Staging systems for most other types of cancer are based on the size of the primary tumor (the first one to develop) and how far the cancer has spread from there. But for patients with AIDS-related Kaposi sarcoma (KS), the most common type in the United States, the outlook 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.

There is no officially accepted system for staging KS like there is for most other forms of cancer. But for AIDS-related KS, most doctors use the AIDS Clinical Trials Group system.

The AIDS Clinical Trial Group system

The AIDS Clinical Trials Group (ACTG) system for AIDS-related KS considers 3 factors:

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

Under each major heading, there are 2 subgroups: either a 0 (good risk) or a 1 (poor risk). The following are the possible staging groups under this system:

T (tumor) status

T0 (good risk): Localized tumor

KS is only in the skin and/or the lymph nodes (bean-sized collections of immune cells throughout the body), 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) or ulceration (breaks in the skin) 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

The immune status is assessed using a blood test known as the *CD4 count*, which measures the number of white blood cells called *helper T cells*.

I0 (good risk): CD4 cell count is 150 or more cells per cubic mm (mm^3).

I1 (poor risk): CD4 cell count is lower than 150 cells per mm^3.

S (systemic illness) status

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

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

No *B symptoms* lasting more than 2 weeks. B symptoms include:

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

And this is true:

- Karnofsky performance status (KPS) 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
- KPS score is under 70
- Other HIV-related illness is present, such as neurological (nervous system) disease or lymphoma

Overall risk group

Once these features have been assessed, patients are assigned an overall risk group (either good risk or poor risk). In fact, since highly active antiretroviral therapy (HAART) became available to treat HIV, the immune status (I) has become less important and is often not counted in determining the risk group:

- Good risk: T0 S0, T1 S0, or T0 S1
- Poor risk: T1 S1

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 Kaposi sarcoma (KS) 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 KS.

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 where the KS is in the body, the person's age and general health, how well their immune system functions, and their response to highly active antiretroviral therapy. Your doctor can tell you how the numbers below apply to you, as he or she is familiar with your particular situation.

As treatment of the HIV infection continues to improve, so does the outlook for people with 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 many years ago. Early in 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 68%. 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.

Research has shown that people who are in good risk groups in the AIDS Clinical Trials Group (ACTG) system have better survival rates than those who are in the poor risk group.

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 and have much more experience treating KS than they did when this disease was quite rare. Many clinical trials have compared different approaches to treatment.

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 health is also a major factor. The presence and severity of other serious health problems can make some treatments a poor choice.

For patients with immune system problems, the most important treatment is keeping the immune system healthy and any related infections under control. Some of the other treatments used for KS are:

- Local therapy
- Radiation therapy
- Chemotherapy
- Biologic therapy (immunotherapy)

In some patients, 2 or more of these treatments are used together.

Based on your options, you may have different types of doctors on your treatment team. These doctors may include:

- An infectious disease specialist: a doctor who treats infectious diseases such as HIV and AIDS.
- A dermatologist: a doctor who treats diseases of the skin
- A radiation oncologist: a doctor who treats cancer with radiation therapy.
- A medical oncologist: a doctor who treats cancer with medicines such as chemotherapy.

Many other specialists may be involved in your care as well, including physician assistants, nurse practitioners, nurses, nutrition specialists, social workers, and other health professionals.

It is important to discuss all of your treatment options as well as their possible side effects with your doctors to help make the decision that best fits your needs. If time permits, it is often a good idea to seek a second opinion. A second opinion can provide more information and help you feel confident about your chosen treatment plan.

Treating immune deficiency and related infections in people with 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 to cause the KS lesions to shrink and to keep them under control.

In organ-transplant patients whose immune systems are suppressed by drugs, decreasing or changing the drugs may be helpful.

New KS lesions are more likely to develop when a patient's blood test results for Kaposi sarcoma 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 bacterial infections. Therefore, it is very important to do what you can to lower your risk of bacterial infections and to treat them promptly if they do occur.

Local therapy for Kaposi sarcoma

Local treatment 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 a person look or feel better. Local therapy is most useful when there are just a few lesions in a very visible area (such as the face). The drawbacks of local therapy are that it doesn't treat lesions anywhere else and it can't keep new lesions from developing.

Topical retinoid treatment

This type of treatment puts medicine directly on the lesion. For example, alitretinoin, a retinoid drug 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 makes it get smaller or go away in 1 to 2 months. Side effects of this gel include skin irritation and lightening of the skin.

Cryosurgery (cryotherapy)

Cryosurgery can be useful for small KS lesions on the face, although it is not as helpful for large or deeper lesions. Liquid nitrogen is applied to the tumor to freeze and kill the cells. After the dead area of skin thaws, it may swell, blister and crust over. The wound may take several weeks to heal, and the skin of the treated area may be lighter after treatment.

Surgery

When a person has only a few, small Kaposi sarcoma lesions, one option may be to remove them with surgery. This can be done in different ways.

Simple excision: For this procedure, the skin is first numbed with a local anesthetic. The tumor is then cut out with a surgical knife, along with some surrounding normal skin. The remaining skin is carefully stitched back together, leaving a small scar.

Curettage and electrodesiccation: This treatment removes a tumor by scraping it with a curette (a long, thin instrument with a sharp looped edge on one end), then treating the area with an electric needle (electrode) to try to destroy any remaining cancer cells. This process can be repeated.

A drawback of surgery is that the lesion might recur (come back) in the same place.

Intralesional chemotherapy

For this treatment, a small amount of a chemotherapy drug is injected directly into the KS lesions. Very little of the drug 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 vinblastine. Sodium tetradecyl sulfate (STS or Sotradecol®) can also be used. Some people may have swelling, blistering, and pain at the injection site with this type of treatment.

Photodynamic therapy (PDT)

This treatment uses a special liquid drug that is applied to the skin. The drug collects in the tumor cells over several hours or days and makes the cells sensitive to certain types of light. A special light source is then focused on the tumor(s), and the cells die. A possible side effect of PDT is that it can make the skin very sensitive to sunlight for some time, so precautions may be needed to avoid severe burns.

For more information on this technique, see our document, *Photodynamic Therapy*.

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 e*xternal beam radiation therapy*. This is the type of radiation therapy used to treat lesions of Kaposi sarcoma (KS).

Radiation therapy is often effective as a type of local therapy to treat KS lesions on or near the surface of the body. Radiation is 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).

For KS lesions on the skin, the form of radiation most often used is called *electron-beam radiation therapy (EBRT).* It uses tiny particles called *electrons* that don't penetrate far past the skin's surface. This limits non-skin side effects. EBRT can also be used to treat large areas of the skin if a person 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, known as *photon radiation*, can penetrate deeper into the body.

Radiation treatments for KS lesions are often given once a week for several weeks. Getting treatment is much like getting an x-ray, but the radiation is stronger. The procedure itself is painless. Each treatment lasts only a few minutes, although the setup time − getting you into place for treatment − takes longer.

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 a small portion of patients 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*.

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").

The systemic chemo 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. 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. The liposomal anthracyclines used in the US to treat KS are liposomal doxorubicin (Doxil®) and liposomal daunorubicin (DaunoXome®).

Other chemotherapy drugs that treat KS include paclitaxel (Taxol®), gemcitabine (Gemzar®), and vinorelbine (Navelbine®). Drugs used less often 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 away completely. Sometimes chemotherapy can be stopped as long as lesions are not causing problems or increasing in size and number. If the KS starts to get worse, treatment can resume.

It can be hard to give chemotherapy for long periods of time in people who have immune system problems (such as AIDS) because chemo drugs can also weaken the immune system. In all patients, it is important to try to improve immune function and treat related infections. This is especially important when giving chemotherapy.

Chemo drugs attack cells that are dividing quickly, which is why they work against cancer cells. But other cells in the body, such as those in the bone marrow, the lining of the mouth and intestines, and the hair follicles, also divide quickly. These cells are also likely to be affected by chemotherapy, which can lead to side effects such as:

- Nausea and vomiting
- Loss of appetite
- Mouth sores
- Diarrhea
- Hair loss
- Increased risk of infection (from too few white blood cells)
- Easy bruising or bleeding (from too few blood platelets)
- Fatigue (from too few red blood cells)

The side effects of chemo depend on the type of drugs, the amount taken, and the length of treatment.

Some drugs can have other side effects. For example, drugs such as vincristine or paclitaxel can damage nerves (called *neuropathy*), sometimes leading to numbness, tingling, or pain, particularly in your fingers and toes. This 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.

Most side effects go away once treatment is finished, but some can last a long time (or even be permanent). Be sure to ask your doctor about the possible side effects from the chemo drugs that you will receive. There are often ways to prevent or lessen these side effects. For example, drugs can be given to help nausea and vomiting. Tell your medical team about any side effects or changes you notice while getting chemo so that they can be treated promptly.

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

Biologic therapy (immunotherapy) for Kaposi sarcoma

Biologic therapy, also known as *immunotherapy*, uses chemicals made naturally by the body (or man-made forms of these chemicals) 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 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.

About half of patients with good immune function improve when given high doses of these drugs, but patients with fevers, infections, weight loss, or low CD4 counts rarely respond to interferon. Even when treatment does work, it can take several months or more to see a response.

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.

Interferon alfa is not often used now because of its side effects and because it doesn't work well in many patients with AIDS. Other forms of immunotherapy are now being studied for use in treating KS (see "What's new in Kaposi sarcoma research and treatment?").

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 Kaposi sarcoma (KS). 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 KS. 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.

You will have to meet some requirements 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. Sometimes they may be the only way to get some 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 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 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 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. You can also check them out on the *Complementary and Alternative Medicine* page of our Web site.

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 sections. 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 and location of the KS lesions
- What kinds of problems the KS is causing
- The person's overall 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 treating the HIV infection with modern anti-AIDS drug combinations. In 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 such as radiation therapy, cryosurgery, or a topical retinoid, may be used if a person has only a few skin 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 given. 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, such as radiation therapy.

Chemotherapy may be used for widespread skin lesions or for KS that is in the lymph nodes, the lungs, or the digestive tract. Liposomal anthracyclines or paclitaxel are the drugs most often used for chemotherapy.

Transplant-related Kaposi sarcoma

In people who have had organ transplants, KS lesions sometimes go away 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 often make KS lesions get smaller.

Skin lesions can be treated with radiation therapy or another local treatment. Most doctors try to avoid giving chemotherapy in KS patients who have had organ transplants. But some patients may agree to take part 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, but it occurs in younger men. It is treated like classic KS.

More treatment information for Kaposi sarcoma

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.

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

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 ask any question 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.

- Has my cancer spread beyond the skin? Has it spread to lymph nodes or other organs?
- 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 AIDS-related KS, is my HIV viral load controlled?
- Are there other tests that need to be done before we can decide on treatment?
- Are there other doctors I need to see?
- How much experience do you have treating this type of cancer?
- What are my treatment choices? What do you recommend? Why?
- What is the goal of the treatment?
- How long will treatment last? What will be done? Where will it be done?
- What are the risks or side effects of treatment? How long are they likely to last?
- How will treatment affect my daily activities?
- What should I do to be ready for treatment?
- Based on what you've learned about my cancer, what is my prognosis (outlook)?
- What will we do if the treatment doesn't work or if the lesions recur?

- What type of follow-up will I need after treatment?
- Where can I find more information and support?

Along with these sample questions, be sure to write down some of your own. For instance, you might want more information about second opinions or if you qualify for any clinical trials.

What happens after treatment for Kaposi sarcoma?

For some people with Kaposi sarcoma (KS), 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 KS, since treatments often do not 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 KS, 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. Read it online or call us at 1-800-227-2345 for a free copy.

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 are having and may do exams and order 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've noticed 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. Talk with your doctor about 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. 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
- Copies of imaging tests (CT or MRI scans, etc.), which can usually be stored on a CD, DVD, etc.
- If you had surgery, a copy of your operative report
- If you stayed 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/or biologic therapy), a list of the drugs, drug doses, and when you took them

Lifestyle changes after Kaposi 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.

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 to develop 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. 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 and other treatment side effects, please see the "Additional resources for Kaposi sarcoma" section.)

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.

Can I lower my risk of the cancer progressing or coming back?

Most people want to know if there are specific lifestyle changes they can make to reduce their risk of cancer progressing or coming back. Unfortunately, for most cancers there is little solid evidence to guide people. For the most part this is an area that hasn't been well studied. Most studies have looked at lifestyle changes as ways of preventing cancer in the first place, not slowing it down or preventing it from coming back.

It is very important for people who have had Kaposi sarcoma to do what they can to keep their immune systems healthy and to limit their risk of infection. If you are HIV-positive, this means being sure to take your antiviral medicines regularly. Talk with your doctor about getting vaccines and other steps you can take to help prevent infections.

Adopting other healthy behaviors such as not smoking, eating well, and maintaining a healthy weight might help as well, but no one knows for sure. However, we do know that these types of changes can have positive effects on your health that can extend beyond your risk of cancer.

How does having Kaposi 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 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 relationships 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 is going through or 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. See the "Additional resources for Kaposi sarcoma" section for other ideas. 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 Kaposi sarcoma stops working

Treatment for Kaposi sarcoma (KS) can often help control the disease or even make the lesions go away, but there is no guarantee that KS will not come back. It is important to be aware that there is always a chance that KS lesions will return, either at the original site or in other places on the skin or internal organs. Advanced KS usually means a person has 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 lesions and can relieve swelling. It can also reduce problems that arise when tumors affect the lungs or gastrointestinal tract. Treatment for KS can bring about important improvements in your quality of life.

If cancer keeps growing or comes back after one kind of treatment, it is possible that another treatment plan might 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 is not getting any better, it 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 might 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 treatment might have about a 1 in 100 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 goal 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 pain caused by the cancer. 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 be treated 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 and this phase of cancer in our documents called *Hospice Care* and *Nearing the End of Life*. They can be read online, or call us at 1-800-227-2345 to have free copies mailed to you.

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 ways to prevent and treat Kaposi sarcoma (KS).

Prevention

Probably the most important advance in the prevention of AIDS-related KS has been the development of drugs that help control HIV infection and AIDS. This has reduced the chance of getting KS.

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 taking drugs to suppress their immune system.

Several drugs used to treat related herpesviruses such as cytomegalovirus (CMV) can also help treat KSHV infections. These drugs stop the KSHV-infected cells from making more of the virus. The drugs seem to lower the risk of developing of KS in patients who are at high risk, although they haven't been found to help treat KS once it has developed.

Treatment

Researchers are studying new and different ways to treat KS.

KS lesions depend on the formation of new blood vessels for their growth. Drugs called *angiogenesis inhibitors*, which block the growth of blood vessels within tumors, may help treat these lesions. For example, the drug bevacizumab (Avastin) has been shown to cause some KS lesions to shrink or stop growing in a small study. Further studies of this drug and other angiogenesis inhibitors are now being done.

Boosting the immune system is another promising approach to treating KS. Interferon alfa was used for many years to help treat KS, although its use is limited today because of its side effects. Studies looking at similar drugs, such as interleukin-12 (IL-12), have shown good results in early studies.

Drugs called *immunomodulating agents* both boost the immune system and affect blood vessel growth, so these drugs may be helpful against KS. The oldest of these drugs, thalidomide (Thalomid), has been shown to help shrink some KS lesions in early studies, but this drug can have side effects that make it hard to take. Related drugs, such as lenalidomide (Revlimid) and pomalidomide (Pomalyst), which tend to have fewer side effects, are now being studied.

Many other new drugs are also being studied for use against KS, including bortezomib (Velcade) and sorafenib (Nexavar).

Of course, research into HIV vaccines and antiretroviral drugs also may have a great impact on AIDS-related KS. KSHV also offers a new target for KS drugs and biologic therapy. Clinical trials are testing whether antiviral drugs that target KSHV may be used for KS.

Additional resources for Kaposi 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 Web site, www.cancer.org.

Related information

Infectious Agents and Cancer

HIV/AIDS (also in Spanish)

Coping with cancer

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

Coping With Cancer in Everyday Life

Talking With Your Doctor (also in Spanish)

Health Professionals Associated With Cancer Care

Distress in People With Cancer

Pain Control: A Guide for Those With Cancer and Their Loved Ones (also in Spanish)

Nutrition for the Person With Cancer During Treatment: A Guide for Patients and Families (also in Spanish)

More about cancer treatments

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

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

Immunotherapy

Photodynamic Therapy

Managing side effects of cancer treatment

Nausea and Vomiting

Anemia in People With Cancer

Fatigue in People With Cancer

Peripheral Neuropathy Caused by Chemotherapy

Insurance and financial issues

Health Insurance and Financial Issues for the Patient with Cancer

In Treatment: Financial Guidance for Cancer Survivors and Their Families (also in Spanish)

Family and caregiver concerns

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

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

What It Takes to Be a Caregiver

Books

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 Web sites*

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

For more information on cancer

National Cancer Institute
Toll-free number: 1-800-422-6237 (1-800-4-CANCER)
TTY: 1-800-332-8615
Web site: www.cancer.gov

> Offers free, accurate, up-to-date information about cancer to patients, their families, and the general public; also helps people find clinical trials in their area

For information on HIV infection and AIDS

AIDSinfo
Toll-free number: 1-800-448-0440 (1-800-HIV-0440)
Web site: www.aidsinfo.nih.gov

> Offers information on HIV treatment and other HIV-related topics, HIV clinical trials information; also available in Spanish

AIDS InfoNet
Web site: www.aidsinfonet.org

> Offers updated fact sheets that can be printed from the Web site. Covers HIV/AIDS topics such as lab tests, treatment, opportunistic infections, preventing HIV, and more. Also in Spanish; some fact sheets are in available other languages

Project Inform
Toll-free number: 1-800-822-7422
Web site: www.projinf.org

> Answers HIV-related questions; offers an information packet for people newly diagnosed with HIV; live answers 10 a.m. to 4 p.m. Pacific time M-F. Includes information on prevention concerns for HIV-infected people, pregnancy and HIV

**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.

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