Kaposi Sarcoma Early Detection, Diagnosis, and Staging

Detection and Diagnosis

Catching cancer early often allows for more treatment options. Some early cancers may have signs and symptoms that can be noticed, but that is not always the case.

- Can Kaposi Sarcoma Be Found Early?
- Signs and Symptoms of Kaposi Sarcoma
- How Is Kaposi Sarcoma Diagnosed?

Stages and Outlook (Prognosis)

After a cancer diagnosis, staging provides important information about the extent of cancer in the body and anticipated response to treatment.

- How Is Kaposi Sarcoma Staged?
- Survival of Patients With Kaposi Sarcoma

Questions to Ask About Kaposi Sarcoma

Here are some questions you can ask your cancer care team to help you better understand your cancer diagnosis and treatment options.

- What Should You Ask Your Doctor About Kaposi Sarcoma?

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 Signs and Symptoms of Kaposi Sarcoma) should see their doctors right away so that the cause can be found as soon as possible and treated, if needed.

- References

See all references for Kaposi Sarcoma

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**Signs and Symptoms of Kaposi Sarcoma**

Kaposi sarcoma (KS) usually appears first as spots (called lesions) on the skin. The lesions can be purple, red, or brown. KS lesions can be flat and not raised above the surrounding skin (called patches), flat but slightly raised (called plaques), or bumps (called nodules). The skin lesions of KS most often develop on the legs or face, but they can also appear in other areas. Lesions on the legs or in the groin area can sometimes block the flow of fluid out of the legs. This can lead to painful swelling in the legs and feet.

KS lesions can also develop on mucous membranes (the linings of certain parts inside the body) such as inside the mouth and throat and on the outside of the eye and inner part of the eyelids. The lesions are usually not painful or itchy.
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 stomach and intestines can cause abdominal pain and diarrhea.

Sometimes KS lesions bleed. If the lesions are in the lung, it can cause you to cough up blood and lead to shortness of breath. If the lesions are in the stomach or intestines, it can cause bowel movements to become black and tarry or bloody. Bleeding from lesions in the stomach and intestines can be so slow that blood isn’t visible in the stool, but over time the blood loss can lead to low red blood cell counts (anemia). This can cause symptoms like tiredness and shortness of breath.

- References
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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.

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. Since biopsy of lesions in these areas can sometimes cause serious bleeding, biopsy is often not done in people already known to have KS.

Chest x-ray

Your 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.

For people 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 you are 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, you are 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.

Because anesthesia is used, you will need someone you know to take you home (not
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 esophagastroduodenoscopy, or EGD)

Upper endoscopy is used to look at the inner lining of the esophagus, the stomach, and the first part of the small intestine. For this procedure, you are first given drugs to make you 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. Because sedation is used for this procedure, you will need someone you know to help you get home afterward (not just a cab).

Colonoscopy

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 (2 to 4 quarts) of a liquid laxative the night before and the morning of the procedure, and spending a lot of time in the bathroom.

Just before the procedure, you will be given intravenous (IV) medicine to make you relaxed or even go to sleep (sedation). 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. Because sedation is used for this procedure, you will need someone you know to help you get home afterward (not just a cab).

Capsule endoscopy

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, you swallow 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 your waist while you go 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. You will likely be told not to eat or drink for about 12 hours before the test.

**Double balloon enteroscopy**

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. For this test, you are given intravenous (IV) medicine to make you relaxed (sedation), and may be even given general anesthesia (so that you are 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 can take hours to complete), but it has the advantage of letting the doctor biopsy any lesions seen. Because sedation (or general anesthesia is used), you will need someone you know to take you home (not just a cab).

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

- References
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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 people 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

References

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Survival of Patients With Kaposi Sarcoma

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 72%. 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.

- References
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**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.

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