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# Kaposi Sarcoma Early Detection, Diagnosis, and Staging

Know the signs and symptoms of Kaposi sarcoma. Find out how Kaposi sarcoma is tested for, diagnosed, and staged.

## 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](#)
- [Tests for Kaposi Sarcoma](#)

## 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.

- [Kaposi Sarcoma Stages](#)
- [Survival Rates for 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.

- [Questions to Ask 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.

## Hyperlinks

1. [www.nccn.org/professionals/physician\\_gls/pdf/kaposi.pdf](http://www.nccn.org/professionals/physician_gls/pdf/kaposi.pdf)

## References

National Comprehensive Cancer Network (NCCN)—AIDS-Related Kaposi Sarcoma. V1.2018 (11/03/2017). Accessed 03/02/2018 from [https://www.nccn.org/professionals/physician\\_gls/pdf/kaposi.pdf](https://www.nccn.org/professionals/physician_gls/pdf/kaposi.pdf)<sup>1</sup>.

Noy A, Dickson M, Gulick RM, Palefsky J, Rubinstein PG, Steir E. Ch. 65 - Acquired Immunodeficiency Syndrome and Cancer. In: Niederhuber JE, Armitage JO, Kastan MB, Tepper JE. *Abeloff's Clinical Oncology*. 5th ed. Philadelphia, PA: Elsevier; 2014.

Yarchoan R, Uldrick TS, Polizzotto MN, Little RF. Ch. 117 - HIV-associated malignancies. In: *DeVita, Hellman, and Rosenberg's Cancer: Principles & Practice of Oncology*. 10th ed. Philadelphia: Lippincott Williams & Wilkins; 2015.

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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](#)<sup>1</sup> in the legs and feet.

KS lesions can also develop on mucous membranes (the inner linings of certain parts of 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.

## Hyperlinks

1. [www.cancer.org/cancer/managing-cancer/side-effects/swelling/lymphedema.html](http://www.cancer.org/cancer/managing-cancer/side-effects/swelling/lymphedema.html)

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## Tests for Kaposi Sarcoma

- [Medical history and physical exam](#)
- [Biopsy](#)
- [Chest x-ray](#)
- [Bronchoscopy](#)
- [Gastrointestinal endoscopy](#)

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](#)<sup>1</sup> 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--associated 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 checked. 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 in the lab.

For skin lesions, the doctor will usually perform a [punch biopsy](#)<sup>2</sup>, which removes a tiny round piece of tissue. If the entire lesion is removed, it is called an [excisional biopsy](#)<sup>3</sup>. 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, such as a [CT scan](#)<sup>4</sup>, 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](#)<sup>5</sup> is a test that 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 or CT scan shows something abnormal. Any of these could mean that KS is in the lungs.

Before bronchoscopy starts, 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.

## 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)**

[Upper endoscopy](#)<sup>6</sup> 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.

## **Colonoscopy**

[Colonoscopy](#)<sup>7</sup> 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, 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 asleep (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.

## **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 through the stool 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 probably 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.

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.

## Hyperlinks

1. [www.cancer.org/cancer/diagnosis-staging/tests.html](http://www.cancer.org/cancer/diagnosis-staging/tests.html)
2. [www.cancer.org/cancer/types/skin-cancer/skin-biopsy-treatment-procedures/punch-biopsy.html](http://www.cancer.org/cancer/types/skin-cancer/skin-biopsy-treatment-procedures/punch-biopsy.html)
3. [www.cancer.org/cancer/types/skin-cancer/skin-biopsy-treatment-procedures/standard-local-excision.html](http://www.cancer.org/cancer/types/skin-cancer/skin-biopsy-treatment-procedures/standard-local-excision.html)
4. [www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/ct-scan-for-cancer.html](http://www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/ct-scan-for-cancer.html)
5. [www.cancer.org/cancer/diagnosis-staging/tests/endoscopy.html](http://www.cancer.org/cancer/diagnosis-staging/tests/endoscopy.html)
6. [www.cancer.org/cancer/diagnosis-staging/tests/endoscopy.html](http://www.cancer.org/cancer/diagnosis-staging/tests/endoscopy.html)
7. [www.cancer.org/cancer/diagnosis-staging/tests/endoscopy.html](http://www.cancer.org/cancer/diagnosis-staging/tests/endoscopy.html)

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## Kaposi Sarcoma Stages

- [How is the stage determined?](#)
- [The AIDS Clinical Trial Group system](#)

After someone is diagnosed with Kaposi sarcoma, doctors will try to figure out if it has spread, and if so, how far. This process is called *staging*. The stage of a cancer describes the extent of the cancer in the body. It helps determine how serious the cancer is and how best to [treat](#)<sup>1</sup> it. **The stage is one of the most important factors in deciding how to treat the cancer and determining how successful treatment might be.**

### How is the stage determined?

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 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 CD4 cells (a specific type of immune cell) in the blood
- The extent of **systemic illness (S)** within the body (how sick is the person from the cancer or the HIV)

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 can sometimes mean a worse prognosis (outcome).

### 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 millimeter (mm<sup>3</sup>).

**I1 (poor risk):** CD4 cell count is lower than 150 cells per mm<sup>3</sup>.

### **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
- 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 evaluated, 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

### **Hyperlinks**

1. [www.cancer.org/cancer/types/kaposi-sarcoma/treating.html](http://www.cancer.org/cancer/types/kaposi-sarcoma/treating.html)
2. [www.nccn.org/professionals/physician\\_gls/pdf/kaposi.pdf](http://www.nccn.org/professionals/physician_gls/pdf/kaposi.pdf)

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## Survival Rates for Kaposi Sarcoma

- [What is a 5-year relative survival rate?](#)
- [Where do these numbers come from?](#)
- [5-year relative survival rates for Kaposi sarcoma](#)

- [Understanding the numbers](#)

Survival rates can give you an idea of what percentage of people with the same type and stage of cancer are still alive a certain amount of time (usually 5 years) after they were diagnosed. They can't tell you how long you will live, but they may help give you a better understanding of how likely it is that your treatment will be successful.

**Keep in mind that survival rates are estimates and are often based on previous outcomes of large numbers of people who had a specific cancer, but they can't predict what will happen in any particular person's case. These statistics can be confusing and may lead you to have more questions. Ask your doctor, who is familiar with your situation, how these numbers might apply to you.**

## What is a 5-year relative survival rate?

A **relative survival rate** compares people with the same type and stage of Kaposi sarcoma to people in the overall population. For example, if the **5-year relative survival rate** for a specific stage of Kaposi sarcoma is 80%, it means that people who have that cancer are, on average, about 80% as likely as people who don't have that cancer to live for at least 5 years after being diagnosed.

## Where do these numbers come from?

The American Cancer Society relies on information from the Surveillance, Epidemiology, and End Results (SEER) database, maintained by the National Cancer Institute (NCI), to provide survival statistics for different types of cancer.

The SEER database tracks 5-year relative survival rates for Kaposi sarcoma in the United States, based on how far the cancer has spread. The SEER database, however, does not group these cancers by the [AIDS Clinical Trial Group system](#) (good risk, poor risk). Instead, it groups them into localized, regional, and distant stages:

- **Localized:** The cancer is confined to one area--for example, the skin, a mucosal surface such as the mouth, or an organ like part of the digestive tract.
- **Regional:** The cancer has grown outside of the place where it started (such as the skin, mouth or digestive tract) and into nearby areas or nearby lymph nodes.
- **Distant:** The cancer has spread to distant parts of the body, such as the lungs or liver.

## 5-year relative survival rates for Kaposi sarcoma

These numbers are based on people diagnosed with Kaposi sarcoma from 2012 to 2018.

SEER Stage	5-Year Relative Survival Rate
Localized	81%
Regional	65%
Distant	47%
All SEER stages combined	75%

### Understanding the numbers

- **These numbers apply only to the stage of the cancer when it is first diagnosed.** They do not apply later on if the cancer grows, spreads, or comes back after treatment.
- **These numbers don't take everything into account.** Survival rates are grouped based on how far the cancer has spread, but your age and overall health, the [type of Kaposi sarcoma](#)<sup>1</sup> you have, your [CD4 cell count](#), how well the cancer responds to treatment, and other factors can also affect your outlook.
- **People now being diagnosed with Kaposi sarcoma may have a better outlook than these numbers show.** Treatments improve over time, and these numbers are based on people who were diagnosed and treated at least 5 years earlier.

### Hyperlinks

1. [www.cancer.org/cancer/types/kaposi-sarcoma/about/what-is-kaposi-sarcoma.html](http://www.cancer.org/cancer/types/kaposi-sarcoma/about/what-is-kaposi-sarcoma.html)

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## Questions to Ask About Kaposi Sarcoma

- [When you're told you have Kaposi sarcoma](#)
- [When deciding on a treatment plan](#)
- [During treatment](#)
- [After treatment](#)

It's important to have frank, open discussions with your cancer care team. They want to answer all of your questions, so that you can make informed treatment and life decisions. For instance, consider these questions:

### When you're told you have Kaposi sarcoma

- Where is the cancer located?
- Has the cancer spread beyond the skin? Has it spread to nearby lymph nodes or other organs?
- What is the cancer's [stage](#)<sup>1</sup> (extent), and what does that mean?
- Will I need other [tests](#)<sup>2</sup> before we can decide on treatment?
- 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?
- Do I need to see any other doctors or health professionals?
- Based on what you've learned about my cancer, what is my prognosis (outlook)?
- If I'm concerned about the costs and insurance coverage for my diagnosis and treatment, who can help me?

## When deciding on a treatment plan

- What are my [treatment options](#)<sup>3</sup>?
- What do you recommend and why?
- How much experience do you have treating this type of cancer?
- Should I get a second opinion? How do I do that? Can you recommend someone?
- What would the goal of the treatment be?
- How quickly do we need to decide on treatment?
- What should I do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- What risks or side effects are there to the treatments you suggest? Are there things I can do to reduce these side effects?
- How might treatment affect my daily activities? Can I still work full time?
- What are the chances the cancer will recur (come back) with these treatment plans?
- What will we do if the treatment doesn't work or if the cancer recurs?
- What if I have transportation problems getting to and from treatment?

## During treatment

Once treatment begins, you'll need to know what to expect and what to look for. Not all of these questions may apply to you, but asking the ones that do may be helpful.

- How will we know if the treatment is working?
- Is there anything I can do to help manage side effects?
- What symptoms or side effects should I tell you about right away?
- How can I reach you on nights, holidays, or weekends?
- Do I need to change what I eat during treatment?
- Are there any limits on what I can do?
- Can I exercise during treatment? If so, what kind should I do, and how often?
- Can you suggest a mental health professional I can see if I start to feel overwhelmed, depressed, or distressed?
- What if I need social support during treatment because my family lives far away?

## After treatment

- Do I need a special diet after treatment?
- Are there any limits on what I can do?
- What other symptoms should I watch for?
- What kind of exercise should I do now?
- What type of follow-up will I need after treatment?
- How often will I need to have follow-up exams and imaging tests?
- Will I need any blood tests?
- How will we know if the cancer has come back? What should I watch for?
- What will my options be if the cancer comes back?

Along with these sample questions, be sure to write down some of your own. For instance, you might want more information about recovery times, or you might want to ask about [clinical trials](#)<sup>4</sup>.

Keep in mind that doctors aren't the only ones who can give you information. Other health care professionals, such as nurses and social workers, can answer some of your questions. To find out more about speaking with your health care team, see [The Doctor-Patient Relationship](#).<sup>5</sup>

## Hyperlinks

1. [www.cancer.org/cancer/types/colon-rectal-cancer/detection-diagnosis-staging/staged.html](http://www.cancer.org/cancer/types/colon-rectal-cancer/detection-diagnosis-staging/staged.html)
2. [www.cancer.org/cancer/types/colon-rectal-cancer/detection-diagnosis-staging/how-diagnosed.html](http://www.cancer.org/cancer/types/colon-rectal-cancer/detection-diagnosis-staging/how-diagnosed.html)
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4. [www.cancer.org/cancer/managing-cancer/making-treatment-decisions/clinical-trials.html](http://www.cancer.org/cancer/managing-cancer/making-treatment-decisions/clinical-trials.html)
5. [www.cancer.org/cancer/managing-cancer/finding-care/the-doctor-patient-relationship.html](http://www.cancer.org/cancer/managing-cancer/finding-care/the-doctor-patient-relationship.html)

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