

# Kaposi Sarcoma: Overview



## What is Kaposi sarcoma?

Cancer starts when cells change (mutate) and grow out of control. The changed (abnormal) cells often grow to form a lump or mass called a tumor. Cancer cells can also grow into (invade) nearby areas. They can spread to other parts of the body, too. This is called metastasis.

Kaposi sarcoma (KS) is a cancer that starts in the cells that form the lining of lymph or blood vessels. KS can cause purple, brown, or red patches on the skin or lumps (tumors) under the skin. These changes are called lesions. They can also form in other parts of the body, like the liver, lungs, stomach, and inside the mouth. KS gets its name from Moritz Kaposi, the doctor who first described it.

There are several types of KS. AIDS-related KS, also called epidemic KS, is the most common type in the U.S. It's most often found in people with HIV/AIDS.

## Who is at risk for Kaposi sarcoma?

A risk factor is anything that may increase your chance of having a disease. The exact cause of someone's cancer may not be known. But risk factors can make it more likely for a person to have cancer. Some risk factors may not be in your control. But others may be things you can change.

Risk factors for KS include:

- Being male
- Ethnic background, such as being of Mediterranean, Italian, or Jewish descent
- Infection with human herpesvirus-8 (HHV-8), also called Kaposi sarcoma-associated herpesvirus (KSHV)
- A weakened immune system. This can be from HIV. It's also caused by the medicines that must be taken after an organ transplant.
- Sexual activity. Men who have sex with men and bisexual men have a higher risk. This might be because they are at higher risk for both HHV-8 and HIV infections.

Talk with your healthcare provider about your risk factors for KS and what you can do about them.

## Can Kaposi sarcoma be prevented?

There's no sure way to prevent KS. But you may be able to lower your risk for it:

- Follow precautions to lower your risk of infection with HIV.
- If you have HIV, treat it.

## Are there screening tests for Kaposi sarcoma?

There are no regular screening tests for KS in people at average risk. Screening tests are done to check for disease in people who don't have symptoms.

If you're at high risk for KS, you may be screened with regular exams to check your mouth and skin for lesions and look for any unusual lumps or other changes.

## What are the symptoms of Kaposi sarcoma?

KS might not cause symptoms, but it most often starts as discolored lesions on the skin. These can be flat, raised, or even small lumps. Lesions most often are first found on the face or legs.

Other symptoms include:

- Lesions in the mouth or in the genital area
- Problems caused by lesions in certain parts of the body, for instance:
  - Lesions in the lungs can cause shortness of breath or coughing up blood
  - Lesions in the digestive tract can cause belly pain, diarrhea, and bloody stool
  - Lesions that block lymph nodes or lymph vessels can cause swelling in different parts of the body, like the legs and feet

Many of these may be caused by other health problems. Still, it's important to see a healthcare provider if you have these symptoms. Only a healthcare provider can tell if you have cancer.

## How is Kaposi sarcoma diagnosed?

The most common way to find KS is when a person sees a healthcare provider because of a discolored patch or lump on their skin. Lesions in the mouth might be found during a dental checkup. You'll be asked about your health history, symptoms, risk factors, and family history of disease. A physical exam will be done.

You may also have:

- Blood tests
- Biopsy of suspicious areas

A biopsy is the only way to know if a lump or change is cancer. Tiny pieces of tissue are removed and sent to a lab to be checked for cancer cells.

After a diagnosis of KS, you'll need more tests. These help your healthcare providers learn more about your overall health, other AIDS-related problems you may have, and the KS. The test results help your healthcare providers decide the best ways to treat the cancer. They're used to find out the stage of the cancer. The stage is how much KS there is and how far it spread (metastasized) in your body. It is one of the most important things to know when deciding how to treat the cancer.

Once your cancer is staged, your healthcare provider will talk with you about what the stage means for your treatment. Be sure to ask your healthcare provider to explain the details of your cancer to you in a way you can understand.

## How is Kaposi sarcoma treated?

Your treatment choices depend on the type of KS you have, test results, how much your immune system is damaged, and the stage of the cancer. The goal of treatment may be to cure you, control the cancer, or help ease problems caused by the cancer. Talk with your healthcare team about your treatment choices, the goals of treatment, and what the risks and side effects may be.

Types of treatment for cancer are either local or systemic. Local treatments remove, destroy, or control cancer cells in one area. Surgery and radiation are local treatments. Systemic treatment is used to destroy or control cancer cells that may have traveled around your body. When taken by pill or injection, chemotherapy and immunotherapy are systemic treatments. You may have just one treatment or a combination of treatments.

Treatment for KS may include:

- Antiretroviral medicines
- Surgery
- Photodynamic therapy (PDT)

- Radiation therapy
- Chemotherapy
- Immunotherapy

Talk with your healthcare providers about your treatment options. Make a list of questions. Think about the benefits and possible side effects of each option. Talk about your concerns with your healthcare provider before making a decision.

## What are treatment side effects?

Cancer treatment like chemotherapy and radiation can damage normal cells. This causes side effects such as hair loss, mouth sores, and vomiting.

Talk with your healthcare provider about side effects you might have and ways to manage them. There are often things you can do and medicines you can take to help prevent or control side effects.

## Coping with Kaposi sarcoma

Many people feel worried, depressed, and stressed when dealing with cancer. Getting treatment for cancer can be hard on the mind and body. Keep talking with your healthcare team about any problems or concerns you have. Work together to ease the effect of cancer and its symptoms on your daily life.

Here are tips:

- Talk with your family or friends.
- Ask your healthcare team or social worker for help.
- Speak with a counselor.
- Talk with a spiritual advisor, such as a minister or rabbi.
- Ask your healthcare team about medicines for depression or anxiety.
- Keep socially active.
- Join a cancer support group.

Cancer treatment is also hard on the body. To help yourself stay healthier, try to:

- Eat a healthy diet, with a focus on high-protein foods.
- Drink plenty of water, fruit juices, and other liquids.
- Be physically active.
- Rest as much as needed.
- Talk with your healthcare team about ways to manage treatment side effects.
- Take your medicines as directed by your team.

## When should I call my healthcare provider?

Your healthcare provider will talk with you about when to call. You may be told to call if you have:

- New symptoms, or symptoms that get worse
- Signs of an infection, such as a fever
- Side effects of treatment that affect your daily function or don't get better with treatment

Ask your healthcare provider what signs to watch for and when to call. Know how to get help after office hours and on weekends and holidays.

## Key points about Kaposi sarcoma

- Kaposi sarcoma (KS) is a cancer that starts in the cells that form the lining of lymph or blood vessels.
- KS might not cause symptoms, but it most often starts as discolored lesions on the skin.
- Types of treatment for cancer are either local or systemic.

## Next steps

- Know the reason for your visit and what you want to happen.
- Before your visit, write down questions you want answered.
- Bring someone with you to help you ask questions and remember what your provider tells you.
- At the visit, write down the name of a new diagnosis and any new medicines, treatments, or tests. Also write down any new instructions your provider gives you.
- Know why a new medicine or treatment is prescribed, how to take it, and how it will help you. Also know what the side effects are.
- Ask if your condition can be treated in other ways.
- Know why a test or procedure is recommended and what the results could mean.
- Know what to expect if you do not take the medicine or have the test or procedure.
- If you have a follow-up appointment, write down the date, time, and purpose for that visit.
- Know how you can contact your provider if you have questions.

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