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**EASY READING**

# If You Have Kaposi Sarcoma

## *Jump to a topic*

- [What is Kaposi sarcoma?](#)
- [How does the doctor know I have Kaposi sarcoma?](#)
- [How serious is my cancer?](#)
- [What kind of treatment will I need?](#)
- [What will happen after treatment?](#)

## **What is Kaposi sarcoma?**

Kaposi sarcoma or KS is a type of cancer that starts in the lining of blood or lymph vessels. It causes purple, red, or brown patches or tumors under or on the skin. Your doctor may call the patches lesions . They're most often in the skin, but can be found other places, too, like inside the mouth, or in the lymph nodes, lungs, or stomach.

## **Are there different kinds of sarcoma?**

There are a few kinds of Kaposi sarcoma (KS). They are much the same, but named for the group of people they start in. The most common kind of KS in the US is AIDS-related KS. It's found in people living with HIV.

Your doctor can tell you more about the type you have.

## **Questions to ask the doctor**

- Why do you think I have KS?

- Is there a chance I don't have KS?
- Would you please write down the kind of KS you think I might have?
- Where is the KS?
- What will happen next?

## How does the doctor know I have Kaposi sarcoma?

Most of the time, Kaposi sarcoma (KS) is diagnosed when a patient sees a doctor about a change in or on their skin. Your doctor will ask questions about your symptoms and do a physical exam.

If signs are pointing to KS, you might need to have more tests. Here are some of the tests you may need:

### Biopsy

A biopsy is the only way to tell for sure if you have KS. In a biopsy, the doctor takes out a small piece of the lesion to check it for cancer cells.

There are different ways to do a biopsy. The type used will depend on the size of the lesion and where it is in your body. Ask your doctor what kind you will need.

### Other tests

**X-rays:** A chest x-ray may be done to see if there's KS in your lungs.

**Bronchoscopy :** If the chest x-ray shows a change or you're coughing up blood and/or having trouble breathing this test may be used to look into your lungs. You will be given drugs to make you sleep while a thin, lighted tube is put down your throat and into your lungs. Your doctor can get a close look at the inside of your breathing tubes and lungs. If a change is seen, a biopsy can be done through the tube.

**Endoscopy:** Some people with KS in their stomach or intestines (digestive tract) have belly pain and see blood in their bowel movements. If the doctor thinks you might have KS in your digestive tract, flexible tubes can be used to look inside your body. These tubes, called scopes may be put in through your mouth or your rectum. The doctor can look at the inside of your digestive tract and do a biopsy through the scope if a change is found. You will be given drugs to make you sleep during these tests.

## Questions to ask the doctor

- What tests will I need to have?
- Who will do these tests?
- Where will they be done?
- Who can explain them to me?
- How and when will I get the results?
- Who will explain the results to me?
- What do I need to do next?

## How serious is my cancer?

If you have Kaposi sarcoma (KS), the doctor will want to find out where it is and how big the lesions are. Your overall health and the health of your immune system (based on your CD4 cell count) are also key factors. This information is used to put you into a risk group: The good risk group or the poor risk group.

Ask the doctor which risk group you're in and what it means for you.

## Questions to ask the doctor

- Do you know the risk group I'm in?
- If not, how and when will you find out the risk group?
- Would you explain to me what my risk group means for me?
- Based on my risk group, how long do you think I'll live?
- What will happen next?

## What kind of treatment will I need?

The treatment that's best for you depends on:

- How well your immune system is working
- Where the lesions are
- How many lesions there are
- The size of the lesions
- Your overall health

- Your feelings about treatment and side effects

For most people with AIDS-related Kaposi sarcoma (KS), treating the HIV with HAART (highly active antiretroviral therapy) keeps the KS under control.

KS is also treated with local treatments, radiation, and/or chemotherapy.

### **Local therapy**

If there are just a few lesions on skin that can be seen (like your face or arms), local therapy might be an option. These treatments only treat the lesion itself. They can include:

- Drugs like creams or gels that are put right onto the lesion
- Chemo that's put right into the lesion using a small needle
- Freezing the lesion to kill the cancer cells
- Minor surgery to remove the lesion
- Using special drugs and lasers (called PDT or photodynamic therapy) to kill the cancer cells
- Radiation to kill the cancer cells

### ***Side effects of local therapy***

These treatments can make your skin red and sore for a while. Your skin may also be lighter when it heals.

Ask the doctor to expect. If you have problems, let your doctors know. Doctors who treat KS should be able to help you with any problems that come up.

### **Radiation treatments**

Radiation uses high-energy rays (like x-rays) to kill cancer cells. It can be used as local therapy and may also be used to treat KS lesions in your mouth or throat or big lesions that cover a lot of your skin. It might be given along with chemo. Radiation can also help treat symptoms like pain and swelling.

A machine aims the radiation beams at the tumor. This is called external beam radiation.

### ***Side effects of radiation treatments***

If your doctor suggests radiation treatment, talk about what side effects might happen. Side effects depend on the type of radiation that's used and the area being treated. Common side effects of radiation are:

- Skin changes where the radiation is given
- Feeling very tired
- Nausea
- Low blood counts

Most side effects get better after treatment ends. Some might last longer. Talk to your cancer care team about what you can expect during and after treatment.

### **Chemo**

Chemo is the short word for chemotherapy, the use of drugs to fight cancer. The drugs are often given through a needle into a vein or taken as pills. These drugs go into your blood and spread through your body.

Chemo may be used to help shrink a tumor, but the KS seldom goes away. Chemo may be started and stopped as needed to keep KS under control.

### ***Side effects of chemo***

Chemo can make you feel very tired, sick to your stomach, and cause your hair to fall out. But these problems go away after treatment ends.

There are ways to treat most chemo side effects. If you have side effects, talk to your cancer care team so they can help.

### **Clinical trials**

Clinical trials are research studies that test new drugs or other treatments in people. They compare standard treatments with others that may be better.

If you'd like to learn more about clinical trials that might be right for you, start by asking your doctor if your clinic or hospital takes part in clinical trials. See [Clinical Trials<sup>1</sup>](#) to learn more.

Clinical trials are one way to get the newest cancer treatment. They are the best way for doctors to find better ways to treat cancer. If your doctor can find one that's studying the kind of cancer you have, it's up to you whether to take part. And if you do sign up for a clinical trial, you can always stop at any time.

### **What about other treatments I hear about?**

When you have cancer you might hear about other ways to treat the cancer or treat your symptoms. These may not always be standard medical treatments. These treatments may be vitamins, herbs, diets, and other things. You may be curious about these treatments.

Some of these are known to help, but many have not been tested. Some have been shown not to help. A few have even been found to be harmful. Talk to your doctor about anything you're thinking about using, whether it's a vitamin, a diet, or anything else.

### **Questions to ask the doctor**

- Will I need to see other doctors?
- What treatment do you think is best for me?
- What's the goal of this treatment? Do you think it could cure the cancer?
- Will treatment include surgery? If so, who will do the surgery?
- What will the surgery be like?
- Will I need other types of treatment, too?
- What will these treatments be like?
- What's the goal of these treatments?
- What side effects could I have from these treatments?
- What can I do about side effects that I might have?
- Will I be able to have children after treatment?
- Is there a clinical trial that might be right for me?
- What about vitamins or diets that friends tell me about? How will I know if they are safe?
- How soon do I need to start treatment?
- What should I do to be ready for treatment?
- Is there anything I can do to help the treatment work better?
- What's the next step?

### **What will happen after treatment?**

You'll be glad when treatment is over. But it's hard not to worry about cancer coming back. Even when cancer never comes back, people still worry about it. For years after treatment ends, you will see your cancer doctor. At first, your visits may be every few months. Then, the longer you're cancer-free, the less often the visits are needed.

Be sure to go to all of these follow-up visits. Your doctors will ask about symptoms, do physical exams, and may do blood tests or other tests to see if the cancer has come back.

Having cancer and dealing with treatment can be hard, but it can also be a time to look at your life in new ways. You might be thinking about how to improve your health. Call us at 1-800-227-2345 or talk to your doctor to find out what you can do to feel better.

You can't change the fact that you have cancer. What you can change is how you live the rest of your life – making healthy choices and feeling as good as you can.

### **For connecting and sharing during a cancer journey**

Anyone with cancer, their caregivers, families, and friends, can benefit from help and support. The American Cancer Society offers the [Cancer Survivors Network \(CSN\)](#)<sup>2</sup>, a safe place to connect with others who share similar interests and experiences. We also partner with [CaringBridge](#)<sup>3</sup>, a free online tool that helps people dealing with illnesses like cancer stay in touch with their friends, family members, and support network by creating their own personal page where they share their journey and health updates.

### **Hyperlinks**

1. [www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html](http://www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html)
2. [csn.cancer.org/](http://csn.cancer.org/)
3. [www.caringbridge.org/](http://www.caringbridge.org/)
4. [www.cancer.org](http://www.cancer.org)

### **Words to know**

**Biopsy** (BY-op-see): Taking out a small piece of tissue to see if there are cancer cells in it.

**Blood count:** A count of the number of cells in a given sample of blood

**Bronchoscopy** (brong-KOS-kuh-pee): Use of a thin, lighted, flexible tube that goes

down the throat into the lungs. The doctor can look through the tube to find tumors or use it to take out a piece of tumor or fluid to test for cancer cells.

**Digestive system:** The collection of organs that process food for energy and rid the body of solid waste matter.

**Lesion** (lee-zhun): An area of abnormal body tissue. May be used to describe a lump, mass, or tumor; also a spot or change in the appearance or texture of skin, such as an open sore, scab, bump, or discolored area.

**Lymph node** (limf node): Small bean-shaped sacs of immune system tissue found throughout the body along **lymph vessels**. They remove cell waste, germs, and other harmful substances from lymph.

**Lymph vessels:** Tiny tubes (like blood vessels) that carry a clear fluid called **lymph** and connect lymph nodes. Lymph carries white blood cells to help fight infection.

**Sarcoma** (sar-KO-muh): Cancer that starts in connective tissue, such as vessels, cartilage, fat, muscle, and bone. Connective tissues connect and support other body tissues and organs.

## How can I learn more?

We have a lot more information for you. You can find it online at [www.cancer.org](http://www.cancer.org) ([www.cancer.org](http://www.cancer.org))<sup>4</sup>. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

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## Written by

The American Cancer Society medical and editorial content team  
([www.cancer.org/cancer/acs-medical-content-and-news-staff.html](http://www.cancer.org/cancer/acs-medical-content-and-news-staff.html))

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