CONDITION

Kaposi sarcoma

Kaposi sarcoma is a cancer linked to HHV-8 that can affect the skin, mouth, lymph system, and internal organs.

WHAT IT IS
HHV-8-associated cancer of blood and lymph vessel cells

BODY SYSTEM
Skin, mouth, lymph system, lungs, and digestive tract

MAIN SYMPTOMS
Coloured skin patches, mouth lesions, swelling, breathing problems

WHAT CAUSES IT
HHV-8 infection plus reduced immune control

HOW IT IS DIAGNOSED
Tissue biopsy with HHV-8 testing

MAIN TREATMENT
Immune restoration, local therapy, or anticancer medicines

CAN IT BE CURED?
Sometimes - localized disease may be eliminated

IS IT AN EMERGENCY?
Sometimes - trouble breathing or major bleeding

LONG-TERM OUTLOOK
Often controllable; internal disease can be serious

Overview

Kaposi sarcoma is a type of cancer that starts in cells lining blood vessels and lymph vessels. Lymph vessels are part of the network that drains fluid from tissues and supports the immune system.

It is caused by infection with human herpesvirus 8, or HHV-8. This virus is also called Kaposi sarcoma-associated herpesvirus. Most people with HHV-8 never develop Kaposi sarcoma. The condition is more likely when the immune system cannot keep the virus under control.

Kaposi sarcoma often appears as red, purple, brown, or dark patches or raised areas on the skin. It can also affect the mouth, lymph nodes, digestive tract, or lungs. Internal Kaposi sarcoma may occur with few or no skin changes.

There are four main clinical forms:

The pattern and speed of the condition differ between these forms. Some cases remain limited to a few skin areas for years. Others affect several organs and require systemic treatment, meaning treatment that works throughout the body.

- HIV-associated Kaposi sarcoma occurs most often when untreated or advanced HIV has weakened the immune system.
- Classic Kaposi sarcoma usually progresses slowly and is most often seen in older people with Mediterranean, Eastern European, or Middle Eastern ancestry.
- Endemic Kaposi sarcoma occurs in parts of sub-Saharan Africa and can affect adults or children.
- Treatment-related Kaposi sarcoma can develop in people taking medicines that suppress the immune system, particularly after an organ transplant.

Symptoms

Skin lesions are the most recognizable sign. They may be flat or raised and can look red, purple, brown, blue-black, or darker than the surrounding skin. Their appearance can be harder to recognize on darker skin tones.

Lesions are often painless and may not itch. They can occur anywhere but commonly affect the legs, feet, face, genital area, or inside the mouth. They may slowly enlarge or join together.

Kaposi sarcoma can block lymph drainage. This may cause swelling, called lymphedema , especially in the feet, legs, face, or genital area. The swelling can become uncomfortable and may make walking or wearing shoes difficult.

Possible symptoms include:

Digestive tract lesions often cause no symptoms. Lung involvement is less common but can be serious. These symptoms can also have many other causes and do not confirm Kaposi sarcoma.

- Skin or mouth patches that grow or multiply
- Leg, foot, facial, or genital swelling
- Pain, bleeding, or difficulty eating from mouth lesions
- Cough, shortness of breath, chest discomfort, or coughing blood
- Abdominal pain, nausea, diarrhea, or unexplained weight loss

- Blood in vomit or stool, or black, tar-like stool

Causes and risk factors

HHV-8 infection is necessary for Kaposi sarcoma to develop, but infection alone is usually not enough. The risk rises when immune control of the virus is weakened.

Important risk factors include untreated or advanced HIV, medicines used to prevent rejection after an organ transplant, and some other immune-suppressing treatments. Age, ancestry, and living in a region where HHV-8 is more common also affect risk.

HHV-8 can be present in saliva and may spread through close contact, including sexual contact. It can also rarely be transmitted through blood or a donated organ. Researchers do not fully understand every route of transmission.

Kaposi sarcoma itself is not passed from one person to another. You cannot catch the cancer by touching a lesion, sharing household items, or spending time with someone who has it.

Having HIV does not mean that you will develop Kaposi sarcoma. Effective antiretroviral therapy, which suppresses HIV, has greatly reduced the number of HIV-associated cases in places where treatment is widely available.

Diagnosis

A skin or mouth lesion may suggest Kaposi sarcoma, but its appearance alone is not enough to confirm the diagnosis. Other conditions can cause similar patches.

Confirmation usually requires a biopsy . During a biopsy, a clinician removes a small piece of tissue so a pathologist can examine it under a microscope. The tissue is generally tested for a protein made by HHV-8-infected cells.

If Kaposi sarcoma is confirmed, further assessment looks at how much of the body is affected. This may include a skin and mouth examination, checking lymph nodes and swelling, and asking about breathing or digestive symptoms.

An HIV test is usually offered if your HIV status is not known. For someone with HIV, blood tests such as a CD4 count and HIV viral load show how well the immune system is working and whether HIV is controlled.

Chest imaging, endoscopy, or bronchoscopy may be used if symptoms suggest internal involvement. Endoscopy uses a flexible camera to examine the digestive tract. Bronchoscopy uses a similar instrument to examine the airways. These tests are not automatically needed for

every skin-limited case.

Treatment and management

Treatment is based on where the lesions are, how quickly they are changing, whether internal organs are involved, and how well the immune system is working. Your comfort, daily activities, and treatment preferences also matter.

For HIV-associated Kaposi sarcoma, effective antiretroviral therapy is central to treatment. Restoring immune control can make lesions shrink and may be enough for limited cases. More extensive or rapidly progressing cancer may also need chemotherapy.

Treatment directed at one area may be used for a small number of bothersome lesions. Options can include radiation therapy, surgical removal, freezing treatment, medicine injected into a lesion, or certain medicines applied to the skin. Local treatment may remove or shrink treated lesions, but it does not prevent lesions elsewhere.

Systemic treatment is considered when Kaposi sarcoma is widespread, progressing quickly, causing substantial swelling, or affecting organs. Chemotherapy medicines such as liposomal anthracyclines or paclitaxel are among the established options. Other targeted or immune-based treatments may be considered in selected situations.

For transplant-related Kaposi sarcoma, the specialist team may adjust immune-suppressing treatment or change to a different medicine. This must be carefully balanced against the risk of organ rejection. Do not stop or alter transplant medicines on your own.

Treatment can control Kaposi sarcoma, but recurrence is possible because HHV-8 remains in the body. Follow-up helps identify new lesions, internal symptoms, or treatment effects early.

Complications

Kaposi sarcoma can interfere with lymph drainage and cause long-term swelling. Severe lymphedema can affect movement, damage the skin, and increase the risk of skin infection.

Lesions may become painful, ulcerated, or bleed. Mouth lesions can make chewing, swallowing, speaking, or wearing dentures difficult.

Digestive involvement can lead to slow blood loss and anemia, which means too few healthy red blood cells. Less often, it causes major bleeding or blockage. Lung involvement can reduce oxygen levels and make breathing difficult.

Treatment may also cause complications. These can include fatigue, infection risk, low blood

counts, nerve symptoms, or skin reactions, depending on the therapy used. The care team usually monitors for these effects and may adjust treatment when needed.

Prevention

There is no vaccine against HHV-8, and Kaposi sarcoma cannot always be prevented. Many people acquire HHV-8 without knowing it, and the routes of transmission are not completely understood.

Preventing HIV or keeping HIV fully suppressed lowers the risk of HIV-associated Kaposi sarcoma. HIV prevention options include condoms, avoiding shared injection equipment, pre-exposure prophylaxis for people with ongoing exposure risk, and prompt assessment for post-exposure prophylaxis after a possible recent exposure.

If you have HIV, taking antiretroviral treatment consistently is the most important way to protect immune function. Missing treatment does not mean Kaposi sarcoma will develop, but prolonged uncontrolled HIV increases the risk.

After an organ transplant, regular follow-up can identify skin changes or other symptoms. Immune-suppressing medicines should only be adjusted by the transplant team.

Living with it and what to expect

The course of Kaposi sarcoma differs between people. Classic Kaposi sarcoma often progresses slowly over years and may need treatment only when lesions cause pain, swelling, bleeding, or distress. HIV-associated Kaposi sarcoma may improve substantially once antiretroviral therapy controls HIV.

Occasionally, lesions or swelling temporarily worsen soon after HIV treatment begins as the recovering immune system reacts to infection. This is called immune reconstitution inflammatory syndrome. It needs medical assessment, but you should not stop HIV treatment unless your care team advises it.

Internal involvement, fast growth, or severe immune suppression usually means closer monitoring and more intensive treatment. Treatment-related Kaposi sarcoma may improve when immune-suppressing therapy can be safely changed.

Follow-up commonly includes examination of the skin and mouth, assessment of swelling, and discussion of breathing or digestive symptoms. People with HIV also need monitoring of viral load and immune function. Scans or internal examinations are generally guided by symptoms and previous findings.

Skin marks may fade slowly after successful treatment and can leave darker pigmentation. Lymphedema may also continue after the cancer is controlled. Compression garments, skin care, movement, and specialist lymphedema support may help when appropriate.

Many people continue usual work, relationships, and activities during or after treatment. Changes in appearance, concerns about HIV stigma, fatigue, or uncertainty about recurrence can still affect emotional well-being. Cancer, HIV, transplant, or lymphedema support services can provide practical and emotional help.

When to get medical help

Arrange a routine appointment if you notice a new unexplained purple, red, brown, or dark skin patch that persists, grows, or multiplies. You should also seek assessment for a lasting mouth lesion, new limb swelling, or changes in a previously diagnosed lesion.

If you already have Kaposi sarcoma, contact your care team promptly about worsening swelling, increasing pain, ulceration, bleeding, fever, persistent cough, abdominal symptoms, or difficulty eating.

Seek urgent medical care for coughing blood, vomiting blood, black tar-like stool, or rapidly worsening shortness of breath.

Call emergency services for severe trouble breathing, fainting, confusion, blue or grey lips, or heavy bleeding that does not stop.

Common questions

Is Kaposi sarcoma a type of skin cancer?

It often appears on the skin, but it starts in cells that line blood and lymph vessels. It can also occur in the mouth, digestive tract, lungs, lymph nodes, and other tissues.

Does Kaposi sarcoma mean I have HIV or AIDS?

No. HIV-associated Kaposi sarcoma is one form, but the condition can also occur in people without HIV. If your HIV status is unknown, testing is an important part of the assessment.

Can Kaposi sarcoma go away with HIV treatment alone?

Limited HIV-associated Kaposi sarcoma may shrink after antiretroviral therapy restores immune control. More extensive, rapidly growing, or organ-involving cancer may need chemotherapy or another treatment as well.

Is Kaposi sarcoma contagious?

The cancer is not contagious. HHV-8, the virus linked to it, can pass between people, but most people with the virus never develop Kaposi sarcoma.

Can Kaposi sarcoma be cured permanently?

A localized lesion can sometimes be eliminated, and immune restoration can produce a long-lasting response. However, HHV-8 stays in the body, so new or recurrent lesions remain possible.

How fast does Kaposi sarcoma spread?

Some forms change very slowly over years. Others progress over weeks or months, particularly when immune suppression is severe or internal organs are affected. Changes in symptoms and immune health help guide follow-up.

Sources

- National Cancer Institute. Kaposi Sarcoma Treatment (PDQ®)-Patient Version
- National Institutes of Health ClinicalInfo. Guidelines for the Prevention and Treatment of Opportunistic Infections in Adults and Adolescents With HIV: Human Herpesvirus-8 Disease
- World Health Organization. Guidelines on the Treatment of Skin and Oral HIV-Associated Conditions in Children and Adults: Evidence and Recommendations on Kaposi Sarcoma . 2014
- Cesarman E, Damania B, Krown SE, Martin J, Bower M, Whitby D. "Kaposi sarcoma." Nature Reviews Disease Primers . 2019;5:9.
- Lebbe C, Garbe C, Stratigos AJ, et al. "Diagnosis and treatment of Kaposi's sarcoma: European consensus-based interdisciplinary guideline." European Journal of Cancer . 2019;114:117-127.