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About Kaposi's sarcoma

Kaposi's sarcoma (KS) is a type of cancer that usually affects the skin and mouth. KS can also affect organs inside the body such as the lungs, liver, stomach, bowel and lymph nodes (glands). It can appear in several parts of the body at the same time.

On this page

- Causes of Kaposi's Sarcoma
- Types of Kaposi's Sarcoma

Causes of Kaposi's Sarcoma

The main cause of KS is a virus called human herpes virus 8 (HHV8). Most people who have this virus never get KS. But people with a weakened immune system who have the virus are more likely to develop KS.

Our immune system is made up of tissues and organs that work together to protect us against infections. Different conditions can cause a weakened immune system. The one most commonly linked with KS is HIV (human immunodeficiency virus), the virus that causes AIDS.

Types of Kaposi's Sarcoma

There are four main types of KS and they're all more common in men than in women.

Epidemic or AIDS-related Kaposi's sarcoma

Epidemic KS is associated with HIV infection. It's the most common of the four types. If HIV develops and the immune system becomes damaged, people who have human herpes virus 8 are more likely to get KS. KS is now less common in the UK because HIV is usually well controlled with treatment.

Classic Kaposi's sarcoma

Classic KS is rare. Like many other cancers it develops without a weakened immune system. It's more common in older men of Mediterranean, Middle Eastern or Jewish descent.

This type of KS is normally only found in the skin, particularly on the lower legs and feet. It's a slow-growing cancer and people with early classic KS may not need treatment.

Endemic or African Kaposi's sarcoma

Endemic KS is found in parts of Africa where human herpes virus 8 is more common. It develops more quickly than classic KS and can affect men, women and children of all ages, although it's more common in men.

Acquired Kaposi's sarcoma (sometimes called transplant Kaposi's sarcoma)

Rarely, people who have a weakened or damaged immune system after an organ transplant develop acquired KS. This is because they need to takes drugs that suppress their immune system (immunosupressants) to reduce the risk of rejecting the donated organ.

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Symptoms and diagnosis of Kaposi's Sarcoma

If you are worried about Kaposi's sarcoma, you should speak to your specialist or GP.

On this page

- Signs and symptoms of Kaposi's Sarcoma
- How Kaposi's sarcoma is diagnosed

Signs and symptoms of Kaposi's Sarcoma

The first symptom of KS is usually skin lesions. Occasionally KS can also affect other parts of the body such as the lymph nodes, lungs, stomach or bowel. When this happens the symptoms will depend on the part of the body that’s affected. Some people may have general symptoms such as fever, weight loss and loss of energy.

Skin lesions

These can range in colour from pink to brown, brown-red or reddish purple. KS can appear as a raised or slightly raised bump (nodule) or a flat area on the skin.

The lesions can develop quickly. Although there may be a single area at first, it’s possible for more than one to appear. Often the lesions merge to form a larger tumour. Any part of the skin can be affected, including the inside of the mouth.

Lymph nodes (glands)

If the lymph nodes are affected by KS, they may become swollen but this generally causes few symptoms.

Swelling in the arms and legs

KS can cause damage to lymph vessels. These are part of our lymphatic system, which helps us fight infection. When the lymph vessels are damaged this can lead to a build-up of fluid in the arms or legs. This is called lymphoedema.

Lung problems

KS in the lungs can cause breathlessness and a cough.

Digestive systen (stomach and bowel) problems

KS may cause symptoms such as feeling sick (nausea) and being sick (vomiting).

Anaemia

Occasionally the lesions may bleed slowly, which over a period of time may cause anaemia (low numbers of red blood cells).

How Kaposi's sarcoma is diagnosed

If you've already been diagnosed with HIV, your own specialist will usually arrange for you to have your symptoms investigated. However, some people may go to their GP with symptoms and will then be referred to a specialist for tests.

Your specialist may suspect you have KS just by looking at the skin lesions, but you'll usually need a biopsy to confirm the diagnosis.

Biopsy

This is usually a quick procedure that can be done in an outpatient department. Your doctor will remove a small piece of the lesion, which will then be examined under a microscope. The area may be sore for a few days, so you may need to take some painkillers.

Further tests

If the biopsy results show that you have KS but you don't have any other symptoms, you may not need any further tests.

You'll usually have further tests if your specialist wants to make sure that there is no KS elsewhere in your body. There are a number of different tests that can be done. Your doctor will explain more about the tests you need and why they're the most appropriate for you.

Tests can include using a thin fibre-optic tube to look at and take biopsies of the inside of the lungs (called a bronchoscopy) or the gullet and stomach (called an endoscopy). You may also have a CT scan.

CT (computerised tomography) scan

A CT scan takes a series of x-rays that build up a three-dimensional picture of the inside of the body. The scan is painless and takes 10–30 minutes. It can help show whether there are any signs of KS in other parts of the body. CT scans use small amounts of radiation, which will be very unlikely to harm you or anyone you come into contact with.

You'll be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye that allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. If you're allergic to iodine or have asthma you could have a more serious reaction to the injection, so it's important to let your doctor know beforehand.

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Treatment for Kaposi's sarcoma

Your treatment will depend on the type of KS you have, the number of lesions you have, where they are, your general health and your age.

On this page

- Epidemic or AIDS-related KS
- Classic KS
- Endemic or African KS
- Acquired or transplant KS
- Clinical trials

Epidemic or AIDS-related KS

You and your specialist will usually consider different factors before making a decision about treatment. These include how well you are, how your immune system is working and if you have general symptoms.

In cases of KS that occur when HIV is diagnosed, treating HIV with special drugs known as highly active antiretroviral therapy (HAART) usually gets rid of KS lesions. HAART works by reducing the level of the virus in the body and improving your immunity. Once treatment with HAART is started, KS often gets better or disappears. But this can take some months to happen.

During this time, if the skin lesions are causing distressing problems, a low dose of radiotherapy can be given to shrink them. Radiotherapy treats cancer by using high-energy rays to destroy the cancer cells.

If KS affects the lungs, stomach or bowel or is causing general symptoms such as fever (high temperatures) and weight loss, you'll usually need chemotherapy. If you're already having anti-HIV treatment when KS is diagnosed or if KS progresses, chemotherapy is usually advised.

Classic KS

Because it's slow-growing and generally doesn't cause any problems, classic KS doesn't usually need to be treated. Radiotherapy is sometimes used to treat large or very visible lesions.

Endemic or African KS

This type of KS is usually treated with chemotherapy.

Acquired or transplant KS

Acquired or transplant KS can sometimes be controlled by stopping or switching the immunosuppressant drugs. If that doesn't work you may need treatment with chemotherapy or radiotherapy.

Clinical trials

Research into new ways of treating Kaposi's sarcoma is going on all the time. Cancer doctors use clinical trials to assess new treatments. Your doctor or specialist nurse can discuss any trials that may be relevant

to your situation.

Before any trial is allowed to take place it must be approved by an ethics committee, which protects the interests of the patients taking part.

Your doctor or a research nurse will discuss the treatment with you, so that you fully understand the trial and what it means to take part. You may decide not to take part or withdraw from a trial at any stage. You will then receive the best standard treatment available.

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Radiotherapy for Kaposi's sarcoma

Radiotherapy uses high-energy x-rays to destroy cancer cells while doing as little harm as possible to normal cells.

Radiotherapy can reduce signs of the KS on the skin. Small lesions may fade completely, and larger and deeper lesions may become smaller and flatter. Radiotherapy also helps improve symptoms such as swelling, pain and bleeding when KS is affecting organs inside the body.

The treatment is usually given as short daily sessions in the hospital radiotherapy department from Monday–Friday, with a rest at the weekend. Each treatment takes 10–15 minutes. For small areas of KS you may need 1–5 treatments, and larger areas may need up to 12.

Your doctor will discuss the treatment with you and explain the side effects you're likely to get. The side effects will depend on the part of the body that's being treated.

Side effects of radiotherapy

Radiotherapy to the skin causes side effects such as soreness of the skin. People with pale skin may notice reddening, and people with darker skin may find that their skin becomes darker. You'll be given instructions on looking after your skin during treatment.

Tiredness is a common side effect of radiotherapy and you may feel tired for some weeks after treatment is over. Make sure you get enough rest and don't overdo things.

The side effects of your radiotherapy will gradually disappear once your treatment has finished.

Watch our radiotherapy video

Dr Vincent Khoo explains how radiotherapy works, and what to expect during treatment.

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Chemotherapy for Kaposi's sarcoma

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. There are different ways in which chemotherapy can be given to treat KS.

On this page

- Chemotherapy injected into the skin
- Liposomal chemotherapy
- Chemotherapy injected into a vein
- Side effects of chemotherapy

Chemotherapy injected into the skin

For small KS lesions that only affect the skin, chemotherapy is injected directly into the skin lesions. This is known as intralesional chemotherapy. It may be used instead of radiotherapy for areas or skin types where radiotherapy might cause darkening of the skin, particularly on the face. Intralesional chemotherapy can also be used for tumours inside the mouth.

The chemotherapy drug vinblastine (Velbe®) is often used and it works best on smaller lesions. Intralesional chemotherapy can shrink skin lesions and make them lighter in colour. In some people lesions may almost disappear completely.

Liposomal chemotherapy

A type of chemotherapy drug called liposomal chemotherapy is recommended as the first systemic treatment for KS. The molecules of the drugs are enclosed (encapsulated) in a fat-based coating known as a liposome. Liposomes are able to travel to the tumour site, where they release the drug. The advantage of this type of chemotherapy is fewer side effects, which means treatment can be given over a longer period.

The liposomal chemotherapy drugs that are commonly used to treat KS are:

- liposomal daunoroubicin (Daunoxome®)
- liposomal doxorubicin (Caelyx®, Myocet®).

These drugs are usually given as drips (infusions) every 2-3 weeks.

Chemotherapy injected into a vein

When KS is widespread on the skin or affects organs inside the body, chemotherapy is usually given into a vein. This is known as intravenous chemotherapy. The chemotherapy drugs travel in the bloodstream and reach KS in different parts of the body. This is sometimes called systemic treatment.

Chemotherapy into the vein is given as a session of treatment, usually over a few hours. This is followed by a rest period, which allows your body to recover from any side effects before you have your next course of chemotherapy. Your specialist will be able to tell you how many courses of chemotherapy you'll have.

Some other chemotherapy drugs which may be used to treat KS are:

- doxorubicin
- vincristine (Oncovin®)
- bleomycin
- etoposide (Etopophos®, Vepesid®)
- paclitaxel (Taxol®).

Side effects of chemotherapy

Chemotherapy can cause side effects but they can often be well controlled with medicines. The side effects usually gradually disappear once your treatment is over. Some of the common side effects are:

Lowered resistance to infection (neutropenia)

Chemotherapy can reduce the number of white blood cells produced by the bone marrow, making you more prone to infection. This effect can begin seven days after treatment. The number of your white blood cells will then increase steadily and usually return to normal before your next cycle of chemotherapy is due.

Contact your doctor straight away if your temperature goes above 38˚C (100.4˚F) or if you suddenly feel unwell, even with a normal temperature.

You'll have a blood test before having more chemotherapy to make sure that your cells have recovered. Occasionally it may be necessary to delay your treatment if the number of white blood cells is still low.

Bruising or bleeding

Chemotherapy can also reduce the production of platelets, which help the blood to clot. Tell your doctor if you have any unexplained bruising or bleeding, such as nosebleeds, bleeding gums, blood spots or rashes on the skin.

Anaemia (low number of red blood cells)

This may make you feel tired and breathless.

Feeling sick (nausea) or being sick (vomiting)

Some of the drugs may make you feel sick or be sick. Your doctor can prescribe effective anti-sickness drugs (anti-emetics) to prevent or greatly reduce this. If they don't work for you let your doctor know, as there are different drugs that can be used.

Soreness and redness of the palms of the hands and soles of the feet

If you're being treated with Caelyx, you may develop red palms and soles of the feet. This is sometimes known as palmar-plantar, or hand-foot syndrome. It's temporary and usually improves once treatment finishes.

Sore mouth and ulcers

Some chemotherapy drugs can make your mouth sore and cause mouth ulcers. Some people find that sucking on ice may be soothing. Drinking plenty of fluids, and cleaning your teeth regularly and gently with a soft toothbrush, can help to reduce the risk of this happening. Tell your nurse or doctor if you have any of these problems, as they can prescribe mouthwashes and medicines to prevent or clear mouth infections.

Hair loss

Some chemotherapy drugs can make your hair fall out. You can ask your doctor whether the drugs you're taking are likely to cause hair loss. If your hair falls out, it will start to grow back again when your treatment finishes.

Skin reaction

Chemotherapy given directly into the skin lesion (intralesional chemotherapy) may cause redness and

swelling in that area. This is not unusual and the skin may break down a little before it begins to heal.

Chemotherapy into a vein (intravenous) can also cause swelling, redness or pain if it leaks out of the vein. This is known as extravasation. Tell your nurse or doctor straight away if this happens.

Tiredness (fatigue)

You may feel tired and generally weak. Allow yourself plenty of time to rest and try not to overdo things.

Although all of these side effects may be difficult to cope with at the time they will usually disappear once your treatment is over

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Living with Kaposi's sarcoma

Your feelings

Most people feel overwhelmed when they are told that they have KS. You're likely to experience many different emotions. These are part of the process many people go through in trying to come to terms with their illness. Reactions differ from one person to another. There's no right or wrong way to feel.

Partners, family and friends often have similar feelings and may also need support.

HIV/AIDS

For some people, KS may be the first sign that they have HIV/AIDS, and coming to terms with this can be very difficult. There are many organisations that offer help and support to people with HIV/AIDS and we've listed some of these below.

Skin Lesions

Coping with skin lesions can be difficult, especially if they're very visible. It may be possible to use skin camouflage to cover small flat skin lesions and make them less noticeable. Some clinical nurse specialists, the British Association of Skin Camouflage and the British Red Cross offer a camouflage make-up service and teach you how to apply it.

Lymphoedema

If you have lymphoedema as a result of KS this can also be hard to cope with, but there are ways in which it can be treated and improved. There are specialist nurses who treat lymphoedema and run clinics that you can be referred to.

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Resources and organisations

You can find links to additional resources or to other organisations that may be able to help below:

National AIDS Helpline

Helpline 0800 567 123 (24 hours)
Provides information, advice and counselling on all aspects of HIV/AIDS.

Terrence Higgins Trust

314–320 Grays Inn Road,
London WC1X 8DP
Helpline 0845 1221 200 (Mon–Fri, 9.30-5.30)
Email info@tht.org.uk
www.tht.org.uk

Offers advice and information on all aspects of HIV/AIDS, including counselling and support, health promotion and benefits advice through its telephone helpline.

National African AIDS Helpline

Helpline 0800 0967 500 (Mon–Fri, 10am–6pm)

A free and confidential helpline offering HIV-related support for people of African ethnicity living in the UK. Has advisers who speak a variety of languages.

Positively UK

347–349 City Road,
London EC1V 1LR
Helpline 020 7713 0222 (Mon–Fri, 10am–1pm and 2–4pm)
Email info@positivelyUK.org
www.positivelyUK.org

Peer support services, including men's and women's support groups, support groups for African people, counselling, a children and family service, and a helpline for people living with HIV.

British Red Cross

44 Moorfields,
London EC2Y 9AA
Tel 0844 871 11 11
Email information@redcross.org.uk
www.redcross.org.uk

Provides a cosmetic camouflage service to teach people living with a disfigurement the simple techniques necessary to apply creams effectively and enable them to feel more confident about their appearance. The service is open to men, women and children through a medical referral from a consultant or GP.

British Association of Skin Camouflage

PO Box 202, Macclesfield SK11 6FP
Tel 01625 871129
Email info@skin-camouflage.net
www.skin-camouflage.net

Provides a cosmetic camouflage service to teach people the techniques of applying creams effectively.

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This information has been compiled using information from a number of reliable sources, including:

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