



KAPOSI'S SARCOMA

What are the aims of this leaflet?

This leaflet has been written to help you understand more about Kaposi's sarcoma. It tells you what this condition is, what it is caused by, what can be done about it, and where you can find out more about it.

What is Kaposi's sarcoma?

Kaposi's sarcoma is a growth of the cells lining lymphatic vessels, caused by a virus in people with a weakened immune system. The virus is called human Herpes virus type 8 (Kaposi sarcoma herpes virus, HHV8). A common cause of the weakened immune system is HIV infection. It is named after Dr Moritz Kaposi, a Hungarian dermatologist, who first described it in 1872. 'Sarcoma' (from ancient Greek 'flesh') means a cancerous growth starting from abnormal cells of connective tissue.

Kaposi's sarcoma can be limited, only affecting the skin, or more extensive with involvement of lymph nodes and internal organs such as the lungs or digestive system. It may be chronic which means it slowly gets worse, or it may rapidly worsen.

What causes Kaposi's sarcoma?

Kaposi's sarcoma can be divided into at least four types:

- Classic (sporadic): rare; affects mainly elderly men of Mediterranean or Eastern European Jewish background, slowly gets worse over many years.
- Endemic (African): affects young adults and less commonly children who live near the African equator.

- HIV-related: HIV is the virus that causes AIDS disease. This is the most common form of Kaposi's sarcoma, linked to advanced AIDS disease, and can be more aggressive than the other forms.
- Iatrogenic: related to taking immunosuppressive medicine treatment, for example following an organ transplant.

It is thought that people who develop classic Kaposi's sarcoma and those with the endemic form were born with vulnerability to the virus that causes it due to their genes. In these groups there is no association with HIV infection.

Is Kaposi's sarcoma hereditary?

Kaposi's sarcoma is not usually hereditary, although there are some reports of the classical form running in, mainly Jewish, families.

What are the symptoms of Kaposi's sarcoma?

Usually, the flat skin lesions of Kaposi's sarcoma do not cause any symptoms. Larger, more raised, lumpy lesions can be uncomfortable or painful, in particular if they have become inflamed or ulcerate. Occasionally bleeding may occur.

Other symptoms depend on which internal organs are involved. With gut involvement, symptoms may include, nausea, vomiting (sometimes with blood), difficulty swallowing, abdominal pain or even bowel obstruction. Involvement of the lungs may cause cough (sometimes with blood) shortness of breath or chest pain.

What does Kaposi's sarcoma look like?

The first noticeable skin changes are often flat bluish-red, brown or pink marks ranging from millimetres to centimetres in size, most often on the legs, neck and back. However, any area of skin can be affected, including inside the mouth, eyes or genitalia. It is typical for Kaposi's sarcoma to be 'multi-focal' (in different areas of the skin at the same time).

As the disease progresses, larger raised plaques or lumps can form, which may ulcerate.

How is Kaposi's sarcoma diagnosed?

If a doctor suspects Kaposi's sarcoma, the diagnosis usually requires confirmation by taking a skin sample (biopsy) under a local anaesthetic. The

skin is then examined under the microscope and tested for Herpes virus type 8. Screening for immunodeficiency, including HIV, is advisable.

Other tests may be arranged by your specialist depending on symptoms or signs of internal organ involvement.

Can Kaposi's sarcoma be cured?

Kaposi's sarcoma is not curable, but can often be effectively controlled for many years, and this is the aim of treatment.

The severity of the disease is related to a number of different factors. More severe disease is associated with the following:

- Kaposi's sarcoma affecting other parts of the body in addition to the skin.
- Immunosuppression.
- Systemic symptoms such as fever, weight-loss, diarrhoea or thrush and other ongoing infections.
- Poor general health.

How can Kaposi's sarcoma be treated?

Treatment depends on the symptoms and extent of the disease.

In HIV-related Kaposi's sarcoma, treatment of the HIV infection can lead to improvement or sometimes disappearance of Kaposi's sarcoma.

If related to immunosuppressive medication, reducing the dose as much as possible, or changing this medication may lead to resolution of lesions.

Classical Kaposi's sarcoma may not require any treatment. If swelling of an affected leg is a problem, compression bandages or stockings may be helpful.

To control Kaposi's sarcoma, which causes symptoms in the skin, or to improve appearance, several local treatment options exist:

- Radiotherapy: destruction of individual lesions with X-rays;
- Cryotherapy: ([see related PIL](#)) freezing with liquid nitrogen causes destruction of individual lesions of Kaposi's sarcoma;

- Laser therapy: different lasers are used to improve the appearance of Kaposi's sarcoma, for example by reducing redness or hyperpigmentation;
- Photodynamic therapy: ([see related PIL](#)) a light-sensitizing cream is applied to the lesion which makes it more sensitive to light which is then directed at the lesion. This destroys the abnormal cells. A local anaesthetic may be required;
- Surgery: excision may be appropriate if there are few lesions. Thicker lesions may be flattened by scraping the raised area off (curettage);
- Intralesional treatment: Injection directly into the patches of Kaposi's sarcoma with chemotherapy or medications, which affect the immune response, may be of benefit;
- Creams containing retinoids (derivatives of Vitamin A, which reduces the formation of new blood vessels) or imiquimod cream, which modify the local immune response, can help.

Skin Camouflage creams ([see related PIL](#)) can be useful covering up lesions of Kaposi's sarcoma. It is advisable that this is not done for a few weeks if injections have been used, or for 2 days after laser treatment.

Severe Kaposi's sarcoma of the skin or the internal organs can be improved with different chemotherapy agents, which are sometimes used in combination. Biologic therapies are also used, and different targeted therapies continue to be developed.

Where can I get more information about Kaposi's sarcoma?

Web links to detailed leaflets:

<http://www.dermnetnz.org/lesions/kaposi-sarcoma.html>

<http://www.patient.co.uk/doctor/kaposis-sarcoma>

<https://www.nhs.uk/conditions/kaposis-sarcoma/>

Skin camouflage organisations:

British Association of Skin Camouflage (NHS and private practice)

Tel: 01254 703 107

Email: info@skin-camouflage.net

Web: www.skin-camouflage.net

Changing Faces

Tel: 0300 012 0276 (for the Skin Camouflage Service)

Email: skincam@changingfaces.org.uk

Web: www.changingfaces.org.uk

Skin Camouflage Network (NHS and private practice)

Helpline: 0785 1073795

Email: enquiries@skincamouflagenetwork.org.uk

Web: www.skincamouflagenetwork.org.uk

For details of source materials used please contact the Clinical Standards Unit (clinicalstandards@bad.org.uk).

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

**BRITISH ASSOCIATION OF DERMATOLOGISTS
PATIENT INFORMATION LEAFLET
PRODUCED NOVEMBER 2014
UPDATED AUGUST 2019
REVIEW DATE AUGUST 2022**