



PATIENT INFORMATION LEAFLET

KAPOSI SARCOMA

WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about Kaposi sarcoma (KS). It tells you what this condition is, what causes it, what can be done about it, and where you can find out more about it.

WHAT IS KAPOSI SARCOMA?

KS is a rare cancer that can occur in the skin and mouth, and sometimes the lymph nodes and internal organs, such as the lungs and gut.

WHAT CAUSES KAPOSI SARCOMA?

KS is caused by a virus called Kaposi sarcoma herpesvirus, also known as Human Herpesvirus type 8 (HHV8).

There are several types of KS:

Classic KS. This type is rare and affects mainly elderly Mediterranean, Middle Eastern or Eastern European Jewish men. The slow-growing skin lesions are typically seen on the lower legs and feet.

HIV-related KS. Human Immunodeficiency Virus (HIV) is a virus that weakens the immune system. The body's immune system helps protect the body against cancer and infections. If a person also has HHV8, then there is a greater chance of them developing KS. This is the most common type of KS, and it is linked to advanced HIV disease or AIDS (acquired immunodeficiency syndrome).

Endemic KS. This type is seen more frequently in young adults and children living near the equator in Africa. Endemic KS is known to be aggressive, which means that it spreads fast.

Iatrogenic KS. This type is also known as transplant-related KS as it affects some people after organ transplantation. The immunosuppressive medicines used to prevent the body from rejecting the transplanted organ(s) increase the risk of developing KS.

IS KAPOSI SARCOMA HEREDITARY?

Generally, KS is not hereditary, although there are some reports of the classical form running in families.

WHAT DOES KAPOSI SARCOMA LOOK AND FEEL LIKE?

KS can look like flat bluish-red, brown or pink marks ranging from millimetres to centimetres in size. Usually, the flat skin lesions of KS do not cause any symptoms. The areas affected most often are the legs, neck and back, however, any area of skin can be affected, including inside the mouth, eyes or genitalia. It is typical for KS to be 'multi-focal' (in different areas of the skin at the same time). Over time, larger raised plaques or lumps can form, which may bleed and become painful and uncomfortable. They can be especially painful if they have become inflamed or have formed ulcers.

Internal KS lesions may also bleed. With gut involvement, symptoms may include nausea, being sick (sometimes with blood), difficulty swallowing, or abdominal (tummy) pain. Involvement of the lungs may cause cough (sometimes with blood), shortness of breath or chest pain.

HOW IS KAPOSI SARCOMA DIAGNOSED?

If a doctor suspects KS, they may take a skin sample (biopsy) under a local anaesthetic. Screening for a problem with the immune system (such as a blood test for HIV) is also likely to be carried out. Other tests may be arranged by your specialist depending on symptoms or signs of internal organ involvement.

CAN KAPOSI SARCOMA BE CURED?

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



HOW CAN KAPOSI SARCOMA BE TREATED?

Treatment depends on the symptoms and extent of the disease. In HIV-related KS, treatment of the HIV infection can lead to improvement or sometimes disappearance of KS. Effective anti-retroviral therapy helps prevent and control HIV-related KS. If related to immunosuppressive medication, reducing the dose as much as possible, or changing this medication, may help. Classical KS may not require any treatment. If swelling of an affected leg is a problem, compression bandages or stockings may be helpful.

Several local treatment options exist:

Radiotherapy: It uses of X-rays and other forms of radiation to destroy cancerous cells, while causing as little harm as possible to normal cells.

Cryotherapy: This treatment uses liquid nitrogen to destroy individual lesions of KS by freezing them.

Intralesional treatment: Injection directly into the patches of KS with chemotherapy or medications, which affect the immune response, may be of benefit.

Retinoid cream: This cream is a derivative of vitamin A. Sometimes, it is used to treat KS.

Imiquimod cream: This cream can treat some skin cancers, including KS.

Laser therapy: Different lasers are used to improve the appearance of KS, for example by reducing **redness** or hyperpigmentation.

Photodynamic therapy: 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).

Skin camouflage can be useful in covering up lesions of KS. Please seek advice from healthcare professionals on their use around the time of treatment for KS. This is especially important if the treatment might inflame or irritate the skin.

Severe KS of the skin or the internal organs can be improved with a variety of medications. Some of the treatments available include chemotherapy agents and biologic therapies.

WHERE CAN I GET MORE INFORMATION ABOUT KAPOSI SARCOMA?

Patient support groups providing information:
Changing Faces

Tel: 0300 012 0275

Email: info@changingfaces.org.uk

Web: www.changingfaces.org.uk

Web links to detailed leaflets:

Web links to other relevant source:

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

Please note that the British Association of Dermatologists (BAD) provides web links to additional resources to help people access a range of information about their treatment or skin condition. The views expressed in these external resources may not be shared by the BAD or its members. The BAD has no control of and does not endorse the content of external links.

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

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