

Kaposi's sarcoma

Last updated May 2012/ Due for review May 2014

Kaposi's sarcoma (KS) is an AIDS-defining cancer and was one of the first recognised HIV-related illnesses in the early 1980s. Unlike most cancers, which start in one place and may then spread to other parts of the body, KS can appear in several parts of the body at the same time. KS results in visible purplish-black patches, or lesions, on the skin, mucous membranes, or internal organs.

It can affect people at all stages of HIV infection, but it is unlikely to be serious as long as the CD4 cell count is above 250. Since the introduction of effective HIV treatment, KS is seen much less often. People with lower CD4 counts are more likely to develop KS that affects internal organs, such as the lymph nodes or lungs, with potentially life-threatening consequences.

KS can also affect some HIV-negative people, and the first cases reported as far back as 1872 were a form of the cancer in older people of eastern Mediterranean origin.

There have been a small number of reports from the US of people developing KS, even when they are doing well on HIV treatment. Nearly all these cases involved gay men who had had HIV for a very long time. The KS they developed was similar to that seen in HIV-negative people. It didn't cause any illness and wasn't dangerous to their health.

KS has been shown to be caused by a virus called human herpes virus 8 (HHV-8), which is also known as Kaposi's sarcoma-associated herpes virus (KSHV). In the presence of other factors – such as immune suppression or other effects of HIV in the body – HHV-8 is thought to encourage normal cells to change into tumour cells.

Both HHV-8 and Kaposi's sarcoma itself are more common among HIV-positive gay or bisexual men, women who were infected with HIV through sex with bisexual men, and people from African communities, than other groups of people with HIV. Earlier ideas about the cause of KS, such as the theory that it was linked to the recreational use of poppers (inhaled nitrites) by gay men, have now been shown to have no foundation in fact.

HHV-8 appears to be sexually transmitted, although it could also be transmitted in other ways. Studies have shown that transmission of HHV-8 increases with the number of years of regular sexual intercourse among gay men, the number of past male sexual partners and a past history of several sexually transmitted infections.

Diagnosis and treatment

The best way to diagnose KS is by taking a sample from a skin lesion. Experienced doctors may diagnose KS simply by looking at it. KS inside the body can often be detected using X-rays and fibre-optic viewing instruments.

You and your doctor may decide not to treat your KS if you only have a few lesions on the skin, if your CD4 count is high and if the lesions are not causing you significant distress or embarrassment.

However, over time KS generally progresses and spreads if left untreated. Doctors will normally recommend treating 'poor prognosis' KS (i.e. KS that is likely to develop rapidly), for example, when there are many lesions, when they affect internal organs, or when your CD4 count is low.

In many cases, the best initial approach to treating KS may be to lower viral load and boost the immune system using HIV treatment. Like most other opportunistic infections, KS often improves or disappears once HIV treatment is started. Anti-HIV drug combinations that include either protease inhibitors (PIs) or a non-nucleoside reverse transcriptase inhibitor (NNRTI) appear to be equally effective at treating and preventing KS.

There is also a range of specific KS treatments. If the KS only affects your skin, you may be able to use 'topical' therapies such as gels or creams, localised radiotherapy, injections of chemotherapy drugs into the lesions, or methods that freeze or burn them.

For more extensive KS, you may be advised to consider 'systemic' treatments that affect the whole body, such as injections of chemotherapy drugs or alpha interferon (also used to treat hepatitis C). Liposomal drugs are just as effective but significantly less toxic than standard chemotherapy drugs.

It is also possible that drugs that work directly against HHV-8 may have a role in treating KS.

Care in the UK

The current British HIV Association (BHIVA) guidelines recommend that if you are diagnosed with KS, you should be referred to a clinic with experience of treating people with HIV and KS, where you would have access to a team of health professionals. NHS targets suggest you should be seen within two weeks of an urgent referral.

Being told you have KS can be a difficult thing to hear. There is no right or wrong way to feel, but it is important to know that support is available to you. As well as talking to the team at your clinic and your friends and family, there are HIV organisations and cancer organisations which can offer support. Your clinic should be able to tell you about local support, but you could also contact a national helpline for more information, advice and support.

The HIV organisation, the Terrence Higgins Trust, runs a helpline called THT Direct, which you can contact on 0808 802 1221 and the cancer organisation Macmillan runs a helpline you can call on 0808 808 0000.