



# Stevens-Johnson syndrome

This information sheet from Great Ormond Street Hospital (GOSH) explains Stevens-Johnson syndrome, what causes it and how it can be treated.

## What is Stevens-Johnson syndrome?

Stevens-Johnson syndrome is a rare condition arising from 'over-reaction' of the immune system to a trigger such as a mild infection or a medicine, leading to blistering and peeling of the skin and surfaces of the eyes, mouth and throat. It is named after the two doctors who described it in the early 20th century.

## What causes Stevens-Johnson syndrome?

The most common triggers for Stevens-Johnson syndrome in children are infections, usually viral. Common infectious triggers include herpes, mumps, flu and the Epstein Barr virus. In adults, reactions to medicines, such as pain killers and antibiotics, are more common. In many cases, the trigger cannot be identified.

Stevens-Johnson syndrome seems to be more common in white people and affects more females than males. It can affect anyone of any age but is most common in children and young adults.

## What are the signs and symptoms of Stevens-Johnson syndrome?

Before the skin symptoms start, many people report feeling generally unwell with a headache and joint pain, accompanied by a cough.

The main feature of Stevens-Johnson syndrome is a skin rash. The affected patches may look like a 'target' with a purple or dark area of skin surrounded by a lighter area. Initially, the skin may be discoloured but then blisters develop which burst and leave sore areas. The rash is not usually itchy. Crops of discoloured areas may develop over a period of several weeks.

The mucous membranes – moist areas of tissue such as the eye, inside of the mouth and throat – are also affected with blisters and ulceration. Ulceration of the mucous membranes has the potential to cause the most serious problems such as dehydration because swallowing is so painful. Heat loss can also occur if large areas of skin are damaged. If the surface of the eye is affected, this could lead to long term damage. If not treated promptly.

## How is Stevens-Johnson syndrome diagnosed?

Stevens-Johnson syndrome has a characteristic appearance so will be diagnosed by clinical examination. Sometimes a skin biopsy – small sample of skin for examination under a microscope – is taken to confirm the diagnosis. Identifying the substance that triggered the overreaction will usually involve isolating an infection from a blood or sputum sample. All medicines may be stopped to identify which, if any, triggered the condition. In many cases, however, the cause cannot be identified.

## How is Stevens-Johnson syndrome treated?

The aim of treatment is to relieve the symptoms and maintain good breathing and hydration levels. In rare severe cases, treatment in intensive care may be required, particularly if breathing support is needed. Hydration may need to be maintained using intravenous (into a vein) fluids.

The sore areas of skin will usually be covered with a non-stick dressing to protect them while they heal. Pain relief will also be required. Mouthwash may also be suggested. The eyes will be treated with lubricant to stop the surface drying out as well as topical steroids and antibiotics to prevent any inflammation and infection.

Each skin lesion tends to take a week or two to heal but new sore areas could develop for several weeks.

## What happens next?

Most people recover fully from Stevens-Johnson syndrome but are at risk of another attack unless the trigger is identified and avoided in future. If a trigger is identified, it is helpful to wear a Medicalert® or equivalent bracelet in case of emergencies.

There is a risk of scarring, especially if the sore area became infected. In the case of mucous membranes, strictures or bands of scar tissue may form narrowing of internal structures such as the throat or airway and if the eye is involved, may affect vision in the long term.

## Further information and support

Stevens-Johnson Syndrome Awareness UK offers advice and support to anyone affected by Stevens-Johnson syndrome. Call them on 07507 855 558 or 07794 743 789 or visit their website at [www.sjsawareness.org.uk](http://www.sjsawareness.org.uk)