CONDITION

Stevens johnson syndrome

Stevens-Johnson syndrome is a rare, life-threatening reaction that causes painful blistering and loss of skin and moist body linings.

WHAT IT IS
Severe immune reaction causing skin and mucous membrane loss

BODY SYSTEM
Skin, eyes, mouth, genitals, and internal organs

MAIN SYMPTOMS
Fever, painful rash, blisters, mouth or eye sores

WHAT CAUSES IT
Usually immune reaction to medicine; sometimes infection

HOW IT IS DIAGNOSED
Clinical examination and skin biopsy

MAIN TREATMENT
Hospital supportive care and immediate medicine withdrawal

CAN IT BE CURED?
Sometimes - illness resolves; damage may remain

IS IT AN EMERGENCY?
Yes - suspected symptoms need hospital care

LONG-TERM OUTLOOK
Most recover, but lasting complications or death can occur

Overview

Stevens-Johnson syndrome, often shortened to SJS, is a serious reaction in which the immune system attacks the skin and mucous membranes. Mucous membranes are the moist linings of areas such as the eyes, mouth, airways, genitals, and anus.

The condition usually begins with fever and flu-like symptoms. A painful rash then develops, followed by blisters and peeling skin. The mouth, eyes, and genitals are commonly affected. SJS is sometimes called Johnson-Stevens disease, although Stevens-Johnson syndrome is the usual medical name.

SJS and toxic epidermal necrolysis, or TEN, are considered different levels of the same condition. In SJS, less than 10% of the body's skin surface detaches. TEN affects more than 30%. Between these levels, the condition is called SJS-TEN overlap.

SJS is a medical emergency because fluid loss, infection, breathing problems, and damage to the eyes or internal organs can develop quickly. Treatment in hospital improves the chance of recovery and allows several specialist teams to protect affected areas.

Symptoms

Early symptoms may appear before the rash. They can include:

The rash may begin as red, purple, or darker patches. On brown or black skin, redness can be difficult to see, but the skin may look purple, grey, or unusually dark. The patches may have darker centres or resemble targets.

The skin often hurts more than an ordinary rash. Blisters can form, and the upper layer may peel away when touched or rubbed. The rash commonly spreads across the face and upper body, although other areas may also be affected.

Painful sores or blisters may develop on the lips and inside the mouth. These can make eating, drinking, or swallowing difficult. Eye involvement can cause redness, pain, swelling, discharge, sensitivity to light, or blurred vision.

Sores around the genitals or anus may make urination or bowel movements painful. If the airways are affected, symptoms can include coughing, chest discomfort, shortness of breath, or low oxygen levels.

Not everyone has every symptom. The combination of fever, skin pain, a spreading blistering rash, and sores affecting the eyes or mouth is especially concerning.

- Fever, tiredness, headache, or aching muscles
- Sore throat, cough, or burning eyes
- Pain when swallowing or reduced appetite
- Unexplained tenderness or pain in the skin

Causes and risk factors

SJS is usually an immune reaction to a medicine. The immune system responds in a harmful way and causes skin cells to die. The reaction is not the same as a minor medicine side effect.

Medicines associated with SJS include some antibiotics like amoxicillin or doxycycline , anti-seizure medicines, allopurinol used for gout, certain anti-inflammatory pain medicines, and some treatments for infections. Most people who take these medicines do not develop SJS.

Symptoms often begin during the first several weeks after starting a medicine, but timing differs. A recently stopped medicine can still be responsible. Prescription medicines, over-the-counter products, and supplements all need to be considered.

Infections can sometimes trigger SJS, particularly in children. Reported triggers include Mycoplasma pneumoniae , which can cause a chest infection, and some viruses. Illness linked mainly to infection may have extensive mouth or eye inflammation with less skin loss and may be classified separately.

Some inherited gene types increase the risk of reactions to particular medicines. This does not mean that SJS itself is directly inherited. Having HIV, cancer, or a weakened immune system may also increase risk. In some cases, no definite trigger is found.

SJS is not contagious. If an infection triggered it, that underlying infection may be able to spread to other people.

Diagnosis

Diagnosis is based on your symptoms, the appearance and extent of the skin changes, and a careful review of recent medicines and infections. Clinicians may ask when each medicine was started, stopped, or increased.

A skin biopsy is usually used to support the diagnosis and rule out other blistering conditions. During a biopsy, a small piece of numbed skin is removed and examined under a microscope.

Blood tests cannot confirm SJS on their own. They can show inflammation, infection, dehydration, or problems involving the kidneys, liver, blood cells, and body salts. Swabs or other infection tests may be taken when an infectious trigger is possible.

The eyes, mouth, genitals, breathing, and percentage of detached skin are assessed. These findings help the hospital team judge severity and plan care. Tests such as chest imaging may be needed if the lungs or airways might be involved.

Treatment and management

SJS requires hospital treatment. People with extensive skin loss may be cared for in an intensive care unit or a specialist burns or dermatology centre.

The suspected medicine is stopped as soon as possible under medical supervision. Identifying all recently used medicines is important, so bringing medicine packets, a current list, or pharmacy records can help. Treatment should not be delayed while the exact trigger is

investigated.

Supportive care protects the body while the skin heals. It may include:

An eye specialist should assess eye symptoms early because inflammation can lead to scarring. Treatment may include frequent lubrication, removal of inflammatory material, medicated eye drops, or procedures to protect the eye surface.

Specialist care may also be needed for genital or urinary involvement. This aims to reduce pain and prevent scar tissue from narrowing openings or joining surfaces together.

Medicines that change the immune response may be considered. These include corticosteroids like prednisone or hydrocortisone , ciclosporin, etanercept, or intravenous immunoglobulin. Evidence about the best option is still developing, and treatment choices differ according to severity, timing, other health conditions, and specialist protocols.

Antibiotics are used when a bacterial infection is suspected or confirmed. They are not automatically needed for every person with SJS.

- Fluids and careful monitoring of body salts
- Pain relief and temperature control
- Gentle wound care and non-stick dressings
- Nutritional support when eating is difficult
- Mouth care and help with swallowing
- Monitoring for infection and organ problems
- Oxygen or breathing support when needed

Complications

During the acute illness, loss of the skin barrier can cause dehydration, changes in body salts, difficulty controlling temperature, and infection. A severe infection can enter the bloodstream and affect the whole body. The lungs, kidneys, liver, or digestive system may also be involved.

Eye complications can include persistent dryness, sensitivity to light, eyelid scarring, lashes growing inward, damage to the clear front surface of the eye, and reduced vision. Regular eye care may be needed even after the skin has healed.

Other possible longer-term effects include:

Not everyone develops lasting complications. The type and severity of long-term effects are linked to which body areas were involved and how much damage occurred.

- Changes in skin colour, scarring, or ongoing sensitivity
- Abnormal nail growth or loss of nails
- Hair loss or reduced sweating
- Dry mouth, dental problems, or difficulty swallowing
- Genital scarring, pain, or sexual difficulties
- Narrowing of the urinary opening
- Long-term cough or breathing problems
- Anxiety, low mood, or distress related to the experience

Prevention

SJS cannot always be prevented. Reactions can occur without warning, and some cases have no confirmed trigger.

After medicine-related SJS, avoiding the responsible medicine is essential because another reaction may be faster or more severe. Closely related medicines may also need to be avoided. The exact names should be recorded in your medical and pharmacy records.

Ask for written information stating which medicine caused or may have caused the reaction. Carrying an allergy card or medical alert identification can help in an emergency. Tell healthcare professionals, dentists, and pharmacists about the reaction before receiving a new medicine.

Do not deliberately take the suspected medicine again to test whether it was responsible. Skin patch tests and other allergy investigations have limited roles and should only be arranged by specialists.

Genetic testing can identify increased risk from certain medicines in some ancestry groups. It is used before selected treatments in specific circumstances, not as a general screening test for everyone.

Living with it and what to expect

The acute illness may last for several weeks. New blistering usually settles after the trigger is removed and the immune reaction comes under control. Skin then grows over exposed areas. Tiredness, weakness, and reduced appetite may continue after leaving hospital.

New skin can remain dry, itchy, sensitive, or different in colour for months. Hair and nails may

take longer to recover, and some nail changes can be permanent. Use of moisturisers, sun protection, and scar care may be discussed during follow-up.

Eye problems can appear or continue after the skin has healed. Follow-up with an eye specialist is important if the eyes were involved, even when vision seems normal. Mouth, genital, breathing, or urinary symptoms may also need specialist review.

Recovery can affect sleep, confidence, work, school, relationships, and emotional health. Rehabilitation, counselling, or peer support may help if the hospital stay or changes in appearance remain distressing.

Many people return to their usual activities, but recovery time differs. Some have few lasting effects, while others need long-term care for their eyes, skin, breathing, or scar-related symptoms. Routine follow-up is used to monitor healing, update medicine records, and address complications early.

When to get medical help

Call emergency services or go to an emergency department now if you develop a painful or rapidly spreading rash with blisters, peeling skin, fever, or sores in the mouth or eyes. This is especially urgent after starting a medicine.

Emergency assessment is also needed for:

Do not drive yourself if you are very unwell. Take all medicine containers or an up-to-date medicine list if it is safe to do so.

After discharge, seek prompt medical advice for increasing wound redness, pus, returning fever, worsening pain, reduced urine, or new eye symptoms. These may indicate infection or another complication.

Routine follow-up is appropriate for ongoing dryness, skin colour changes, nail problems, mild scar discomfort, or emotional concerns that are not rapidly worsening. Keep planned appointments with dermatology, eye care, and other specialists.

- Trouble breathing, swallowing, or staying awake
- Severe eye pain, light sensitivity, or sudden vision changes
- Signs of dehydration, such as very little urine or marked dizziness
- Widespread skin tenderness or detachment
- Rapid swelling of the face, tongue, or throat

Common questions

Is Stevens-Johnson syndrome contagious?

No. SJS is an immune reaction and cannot spread through touching, sharing items, or breathing the same air. An infection that triggered the reaction may be contagious.

Can Stevens-Johnson syndrome come back?

Yes. Recurrence is possible, especially after taking the same trigger medicine or a closely related medicine. Clear allergy records and medical alert information reduce the chance of accidental re-exposure.

Does the skin grow back after SJS?

The skin often grows back over several weeks. It may remain dry, sensitive, scarred, or lighter or darker than before. Eye and mucous membrane damage may take longer to heal or may be permanent.

What is the difference between SJS and toxic epidermal necrolysis?

They are parts of the same severe reaction. SJS involves less than 10% skin detachment, while toxic epidermal necrolysis involves more than 30%. Involvement between these levels is called SJS-TEN overlap.

Can I take medicines again after SJS?

Many medicines can still be used, but the suspected trigger and sometimes related medicines must be avoided. A specialist or pharmacist can help create a clear list of safe and unsafe options. Never retake the suspected trigger as a test.

Can Stevens-Johnson syndrome be fatal?

It can be, particularly when extensive skin loss, serious infection, or organ damage occurs. Prompt hospital care is important. Many people survive, although some have long-term complications.

Sources

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