



Diseases and Conditions

Stevens-Johnson syndrome

By Mayo Clinic Staff

Stevens-Johnson syndrome is a rare, serious disorder of your skin and mucous membranes. It's usually a reaction to a medication or an infection. Often, Stevens-Johnson syndrome begins with flu-like symptoms, followed by a painful red or purplish rash that spreads and blisters. Then the top layer of the affected skin dies and sheds.

Stevens-Johnson syndrome is a medical emergency that usually requires hospitalization. Treatment focuses on eliminating the underlying cause, controlling symptoms and minimizing complications.

Recovery after Stevens-Johnson syndrome can take weeks to months, depending on the severity of your condition. If it was caused by a medication, you'll need to permanently avoid that drug and others closely related to it.

Stevens-Johnson syndrome symptoms include:

- Facial swelling
- Tongue swelling
- Hives
- Skin pain
- A red or purple skin rash that spreads within hours to days
- Blisters on your skin and the mucous membranes of your mouth, nose, eyes and genitals
- Shedding of your skin

If you have Stevens-Johnson syndrome, several days before the rash develops you may experience:

- Fever

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- Sore mouth and throat
- Fatigue
- Cough
- Burning eyes

When to see a doctor

Stevens-Johnson syndrome requires immediate medical attention. Seek emergency medical care if you experience any of the following signs or symptoms:

- Unexplained widespread skin pain
- Facial swelling
- Blisters on your skin and mucous membranes
- Hives
- Tongue swelling
- A red or purplish skin rash that spreads
- Shedding of your skin

Stevens-Johnson syndrome is a rare and unpredictable reaction. Your doctor may not be able to identify its exact cause, but usually the condition is triggered by a medication or an infection.

Medication and therapy causes

Drugs that can cause Stevens-Johnson syndrome include:

- Anti-gout medications, such as allopurinol
- Pain relievers such as acetaminophen (Tylenol, others), ibuprofen (Advil, Motrin IB, others) and naproxen sodium (Aleve)
- Medications to fight infection, such as penicillin
- Medications to treat seizures or mental illness (anticonvulsants and antipsychotics)
- Radiation therapy

Infectious causes

Infections that can cause Stevens-Johnson syndrome include:

- Herpes (herpes simplex or herpes zoster)
- Pneumonia
- HIV

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- Hepatitis

Factors that increase your risk of developing Stevens-Johnson syndrome include:

- **Viral infections.** Your risk of Stevens-Johnson syndrome may be increased if you have an infection caused by a virus, such as herpes, viral pneumonia, HIV or hepatitis.
- **Weakened immune system.** If you have a weakened immune system, you may have an increased risk of Stevens-Johnson syndrome. Your immune system can be affected by an organ transplant, HIV/AIDS and autoimmune diseases, such as lupus.
- **A history of Stevens-Johnson syndrome.** If you've had a medication-related form of this condition, you are at risk of a recurrence if you use that drug again.
- **A family history of Stevens-Johnson syndrome.** If an immediate family member has had Stevens-Johnson syndrome or a related condition called toxic epidermal necrolysis, you may be more susceptible to developing Stevens-Johnson syndrome too.
- **Having a certain gene.** If you have a gene called HLA-B 1502, you have an increased risk of Stevens-Johnson syndrome, particularly if you take certain drugs for seizures or mental illness. Families of Chinese, Southeast Asian or Indian descent are more likely to carry this gene.

Stevens-Johnson syndrome complications include:

- **Secondary skin infection (cellulitis).** Cellulitis can lead to life-threatening complications, including sepsis.
- **Blood infection (sepsis).** Sepsis occurs when bacteria from an infection enter your bloodstream and spread throughout your body. Sepsis is a rapidly progressing, life-threatening condition that can cause shock and organ failure.
- **Eye problems.** The rash caused by Stevens-Johnson syndrome can lead to inflammation in your eyes. In mild cases, this may cause irritation and dry eyes. In severe cases, it can lead to extensive tissue damage and scarring that results in blindness.
- **Damage to internal organs.** It's unusual for this condition to affect internal organs. But it may cause inflammation of the lungs, heart, kidneys or liver.
- **Permanent skin damage.** When your skin grows back following Stevens-Johnson syndrome, it may have abnormal bumps and coloring. And you may have scars. Lasting skin problems may cause your hair to fall out, and your fingernails and toenails may not grow normally.

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Stevens-Johnson syndrome is an emergency medical condition. If you have signs and symptoms, call 911 or emergency medical help, or go to an emergency room immediately.

If you have time before you go:

- **Put in a plastic bag all the medications you've taken in the last three weeks**, including prescription and over-the-counter (nonprescription) drugs. Take the bag with you, as it may help the doctor figure out what triggered your condition.
- **Ask a family member or a friend to come along**, if he or she is available immediately. You may want to share relevant health information about yourself with him or her, so this person can help you when you talk with your doctor.

Questions your doctor may ask include:

- Have you had a flu-like illness recently?
- What other medical conditions do you have?
- What medications have you taken in the last three weeks?

While you're in the hospital, you'll likely have questions for your doctor. It might help to keep a list of questions you have, such as:

- What caused my condition?
- How do I keep from having this reaction again?
- What restrictions do I need to follow?
- I have other medical conditions. How do I manage them together?
- How long will it take my skin to heal?
- Am I likely to have any permanent damage?

Tests and procedures used to diagnose Stevens-Johnson syndrome include:

- **Physical exam.** Doctors often can identify Stevens-Johnson syndrome based on your medical history, a physical exam, and the disorder's signs and symptoms.
- **Skin test.** To confirm the diagnosis, your doctor may remove a sample of skin for laboratory testing (biopsy).

Stevens-Johnson syndrome requires hospitalization, often in an intensive care unit or burn unit.

Stopping nonessential medications

The first and most important step in treating Stevens-Johnson syndrome is to discontinue any medications that may be causing it. Because it's difficult to determine exactly which

drug may be causing the problem, your doctor may recommend that you stop taking all nonessential medications.

Supportive care

Supportive care you're likely to receive while hospitalized includes:

- **Fluid replacement and nutrition.** Because skin loss can result in significant loss of fluid from your body, replacing fluids is an important part of treatment. You may receive fluids and nutrients through a tube placed through your nose and advanced into your stomach (nasogastric tube).
- **Wound care.** Cool, wet compresses will help soothe blisters while they heal. Your health care team may gently remove any dead skin and place a medicated dressing over the affected areas.
- **Eye care.** You may also see an eye specialist (ophthalmologist).

Medications

Medications commonly used in the treatment of Stevens-Johnson syndrome include:

- Pain medication to reduce discomfort
- Medication to relieve itching (antihistamines)
- Antibiotics to control infection, when needed
- Medication to reduce skin inflammation (topical steroids)

If the underlying cause of Stevens-Johnson syndrome can be eliminated and the skin reaction stopped, new skin may begin to grow over the affected area within several days. In severe cases, full recovery may take several months.

If you have had Stevens-Johnson syndrome, be sure to:

- **Know what caused your reaction.** If your condition was caused by a medication, learn its name and that of closely related medications.
- **Inform your health care providers.** Tell all your health care providers that you have a history of Stevens-Johnson syndrome. If the reaction was caused by a medication, tell them which one.
- **Wear a medical information bracelet or necklace.** Have information about your condition and what caused it inscribed on a medical information bracelet or necklace. Always wear it.
- **If you are of Asian descent, consider genetic testing before taking certain drugs.** If you are of Chinese, Southeast Asian or Indian descent, talk with your doctor before taking carbamazepine (Carbatrol, Tegretol). This drug is useful to treat

epilepsy, bipolar disorder and other conditions. But people with a gene called HLA-B 1502 have an increased risk of Stevens-Johnson syndrome if they take this drug. The Food and Drug Administration recommends people of Asian ancestry undergo genetic testing before taking carbamazepine.

- **If you've had this condition, avoid the medication that triggered it.** If you've had Stevens-Johnson syndrome and your doctor told you it was caused by a medication, avoid that drug and others like it. This is key to preventing a recurrence, which is usually more severe than the first episode and can be fatal.

Your family members also might want to avoid this drug because some forms of this condition have a genetic risk factor.

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