

## WHAT IS SJS/TENS?

Stevens-Johnson Syndrome (SJS) and its more severe form Toxic Epidermal Necrolysis (TEN) are very serious cutaneous (skin) reactions that may be caused by a viral or other infection, but are more commonly caused by a reaction to a drug (Adverse Drug reaction (ADR)). ADRs can range from mild to very severe and can be life threatening, with SJS and TEN being the most serious.

SJS was first discovered in 1922 by pediatricians Albert M. Stevens and Frank C. Johnson after diagnosing a child with a severe ADR affecting the eyes and mouth.

The difference between SJS and TEN can be classified by the amount of skin blistered during the reaction. For example, with SJS there can be between 1-10% of skin detachment. Between 10-30% is an overlap of SJS and TEN and greater than 30% skin detachment is classed as TEN.

A lot of research is now being conducted into ADRs as they are a major problem. Depending on the severity of the ADR, quality of life can be affected in many different ways.

## WHAT CAN CAUSE SJS?

**Although all medications including over-the-counter and herbal medicines** have the potential to cause SJS/TEN, the most commonly implicated are:

- **Anti-convulsants** (drugs used for epilepsy), for example:  
Carbamazepine  
Lamotrigine  
Phenytoin
- **Antibiotics**, for example:  
Penicillin  
Cephalosporin  
Sulphonamides
- **Non-Steroidal Anti-inflammatory medications (NSAIDs)**, for example:  
Ibuprofen

- **Anti-gout medications**, for example  
Allopurinol

Other Causes include Viral, Bacterial and Fungal Infections.

## WHO CAN GET SJS/TEN?

**Any age group** can be affected by SJS/TEN. However it has been highlighted that older people are potentially more at risk as they are more likely to use drugs associated with the disease.

Although it is difficult to clearly ascertain specific risk groups, with advances in genetic research it has become evident that people from a specific ethnic background that have a certain gene type, may be at a higher risk when treated with some of the medications mentioned above. Screening for these genes among specific populations before commencing medications, may help to prevent SJS/TEN.

## KNOW THE SIGNS!

Recognition of the early symptoms of SJS/TEN, accurate diagnosis and prompt medical attention are the most invaluable tools in minimising the possible long-term effects.

**Initial symptoms may be non-specific in nature and may include:**

- Fever
- Malaise
- Flu-like symptoms

**Further symptoms may follow and may involve:**

- Mucous membranes – blisters to the mouth, eyes, ears, nose, genital area
- Swelling of eyelids and itchy, red eyes
- Blistering rash to variable percentage of the body

**If it is suspected that the reaction is due to a drug, the symptoms can take one or two weeks to manifest from the first time the patient takes the**

**drug. Always contact your doctor before deciding to stop a drug.**

## WHAT ARE THE RISKS?

SJS and TEN are life-threatening reactions. If left untreated they can result in many long term complications including dry-eye syndrome, photophobia and permanent blindness. Damage to the lungs may also occur leading to inflammation of the airways and lung. Other complications may include loss of nail beds, scarring of mucous membranes, arthritis and chronic fatigue syndrome. Skin detachment can also be extremely severe, requiring treatment at a burns unit. Collectively the symptoms mentioned can be fatal and if left untreated can lead to death.

## WHAT TREATMENT IS AVAILABLE?

**Seek medical attention as soon as possible!**

First and foremost the culprit drug must be stopped immediately to prevent worsening of symptoms. Treatment for SJS/TEN is good supportive care. Depending on the severity and the parts of the body affected, the individual will be referred to a number of specialist teams/units to include; burns, infectious disease, ophthalmology and dermatology. The individual may be prescribed:

- IV fluids and high calorie formulas to promote healing
- Antibiotics when necessary to prevent secondary infections such as sepsis
- Pain relief medications such as morphine

Most SJS patients can be managed in the Intensive Care Unit; however patients with TEN should be treated in a burn unit.

It is important to highlight the importance of recording ADR's whether mild or severe. The reporting system in the UK is called the Yellow Card Reporting System and is accessible to the public via number of methods:

- Use the online Yellow Card form at [www.mhra.gov.uk/yellowcard](http://www.mhra.gov.uk/yellowcard)
- On a Yellow Card form found in pharmacies and GP surgeries
- Call the Yellow Card freephone on 0808 100 3352

## SJS AWARENESS UK

SJS Awareness UK is a not-for-profit organisation committed to raising awareness of SJS in the United Kingdom. The organisation aims to support survivors and their families to overcome the physical, emotional and psychological challenges they may experience following an episode of SJS/TEN. Our aim is to disseminate valuable information about SJS/TEN to members of the public and medical professionals regarding early recognition, available treatments and therapies that may prove beneficial to sufferers. The organisation also has close links with the University of Liverpool, keeping in touch with the most up to date research being conducted in this area.

## OUR SERVICES to bridge the gap include...

- **Support** survivors and their families to overcome emotional and psychological challenges they may experience following an episode of SJS/TEN
- **Advice & Information**
  - On Disability and Welfare Rights
  - on support available for survivors wishing to pursue their educational goals
  - for those who need some reasonable adjustments to improve their working environment
- **Promote** platforms for social inclusion to eradicate the feeling of isolation – Tele-support group, local support group and social media
- **Provide** information for support agencies who get involved with an SJS/TEN survivor



## CONTACT US

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### Further information is available at:

[www.patient.co.uk](http://www.patient.co.uk)

[www.sjsupport.org](http://www.sjsupport.org)

[www.mayoclinic.com](http://www.mayoclinic.com)

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**IT'S IMPORTANT TO READ THE INFORMATION  
LEAFLET THAT COMES WITH YOUR  
MEDICATION: IT MAY HELP YOU TO  
PROMPTLY RECOGNIZE WHEN YOU ARE  
HAVING A POSSIBLE REACTION TO THAT  
MEDICATION!**

# Stevens - Johnson Syndrome (SJS) & Toxic Epidermal Necrolysis (TEN) Factsheet

*...it's a medical emergency!*

