

**We** are glad you survived this life-threatening condition! Be assured you are not alone though it is considered to be a very rare condition with an occurrence of about 2 or 3 in a million in the UK/ Europe.

The content of this leaflet has been obtained from SJS/TEN survivors in the UK and the Stevens-Johnson Syndrome Foundation in the USA.

It is intended for information only.

Stevens - Johnson Syndrome (SJS) is a life threatening condition that affects the skin and mucus membranes in the body. This is usually caused by a severe allergic reaction to drugs, though it can also be triggered by other causes such as viral infections. Toxic Epidermal Necrolysis (TEN) is a more severe form of SJS due to the degree of skin involvement.

During an episode of SJS/TEN, the patient's skin often appears to be like that of a person suffering from chemical burns while other parts of their body including internal organs may also be affected.

Once you make a recovery from this initial episode of SJS/TEN, you may experience various long term effects which could alter your lifestyle for the foreseeable future. The onset of these effects can be progressive and varies in each individual case.

## Other Survivors have reported problems with...

**FATIGUE** has been the most common long term effect experienced by most survivors. The majority of survivors say they are recurrently exhausted for doing very little or nothing at all.

**THE EYES** – about 95% of SJS/TEN survivors could be visually impaired in the long term. The common effect of SJS/TEN on the eye include *Corneal Scarring, Dry Eyes, ingrowing eyelashes and Photosensitivity as well as other complications*. The deterioration of sight for some have been progressive while others have experienced severe visual problems immediately. This sight problem can be described as a “functional blindness” in the sense that most survivors may have a residual vision (about 1-15% of sight) however, this is usually blurred and affected by environmental conditions such as **heat, bright lighting and sunlight thereby making it undependable.**

**EARS, NOSE & THROAT** - some survivors have had problems with their hearing, others have lost the lining in their nose and others have problems with swallowing.

**THE MOUTH** – some have had scarring or lost the lining on their tongue and mouth

thereby making it unbearable to have foods containing acid such as oranges.

**THE TEETH** – some survivors say they have had dental problems like gum disease and tooth decay after their first experience with SJS/TEN.

**NAILS** – those who lost their finger and toe nails said it took several months for their nail beds to grow back healthily.

**HAIR** – some survivors have reported problems with hair loss

**SKIN** – another common problem reported by most SJS/TEN survivors is dry skin, itching and being sensitive to heat and sunlight. They tend to be more comfortable in cool temperatures.

**Other health problems** reported by some survivors include **Arthritis, Post Traumatic Stress, Urological problems, Memory problems amongst other** complications. Most SJS/TEN survivors have been made aware that they are prone to Scarring.

### Please report your allergic reaction

- using 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 0800 100 3352**

## SJS AWARENESS UK

SJS Awareness UK is a charitable company committed to raising awareness of SJS in the United Kingdom. The organisation provides support for 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

### Address:

SJS Awareness UK  
Starting Point, 16a Pickering Road  
Barking, Essex  
IG11 8PG

### Email:

[info@sjsawareness.org.uk](mailto:info@sjsawareness.org.uk)

### Phone:

0203 288 2235 / 07507 85 55 58

### Website:

[www.sjsawareness.org.uk](http://www.sjsawareness.org.uk)

### Further information is available at:

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

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

**IT'S IMPORTANT to notify your GP and other medical professionals of the allergies you have and avoid the specific medication that caused your episode of SJS/TEN.!!!**

# WHAT YOU NEED TO KNOW: THE FACTS OF SURVIVING SJS/TEN

