



SJS / TEN Patient Information Leaflet

What are the aims of this leaflet?

This leaflet has been written to help you understand SJS (Stevens-Johnson syndrome) and TEN (toxic epidermal necrolysis). These two names are used to describe the milder form, SJS, and the severe form, TEN, of the same condition. The two names are often used together, SJS/TEN, to describe all cases. This leaflet tells you what SJS/TEN is, what causes it, and what therapy is used to treat it. Information in this leaflet should also provide guidance for you when you leave hospital.

What is SJS/TEN?

SJS/TEN is a rare, severe skin reaction characterised by a blistering rash in combination with inflammation of the eyes, mouth, nose and genitalia. The upper layer of the skin (called the epidermis) can become detached leaving the lower layer (the dermis) exposed. In adults this is usually a reaction to medication, however in children both infection and medication are important triggers.

What causes SJS/TEN?

Almost any medication can cause SJS/TEN including over-the-counter medications and herbal/natural preparations. Infections that can commonly cause SJS/TEN in children include the herpes simplex (cold sore) virus, *Mycoplasma pneumoniae*, and other respiratory tract infections. Sometimes there is no clear trigger identified. It is not clear why some people react in this intense manner, but we believe it may be due to an extreme allergic response.

Is SJS/TEN hereditary?

A tendency to SJS/TEN is not passed down from generation to generation. However, there can be a genetic predisposition in certain ethnic populations.

What are the symptoms of SJS/TEN?

The earliest features of SJS/TEN include flu-like symptoms: sore throat, fever, and red, sore eyes. Over the next few days a painful red or purple rash appears, accompanied by inflammation of the mouth, lips, eyes and genitalia. The rash usually starts to blister at this stage. The amount of skin involvement and degree of blistering extends over the following days.

What does SJS/TEN look like?

Blistering in SJS/TEN occurs on skin which is red or purple. In SJS the blistering involves less than 10% of the body surface area (BSA); in TEN the blistering is much more extensive and will involve more than 30% of the BSA. Involvement of the eyes can cause redness, weeping and crusting of the eyelids. Involvement of the mouth can result in extensive ulceration which is usually associated with crusted, bleeding lips.

How will SJS/TEN be diagnosed?

There are no specific blood tests for SJS/TEN. A definitive diagnosis of SJS/TEN is made from the doctors' assessment of the skin, usually along with a skin biopsy. A biopsy involves taking a very small sample of skin and examining it with a microscope.

How can SJS/TEN be treated?

Early treatment is important. If a drug is suspected to be the cause, this must be stopped immediately.

You will be admitted to hospital, and if the skin loss is extensive you will be taken to an intensive care unit or a burns unit.

In hospital, the treatment received is aimed at:

- minimising further skin loss
- preventing infection
- providing hydration and nutrition
- providing pain relief.

This is called supportive care. The principle is to ensure that the skin can heal as quickly as possible once the allergic reaction has finished.

As well as the above, topical treatments to the skin, eyes and mouth consisting of ointments and, where necessary, dressings will be given.

There is no clear evidence to show the benefit of any treatment with tablets or injections. Withdrawing the culprit drug and high-quality, multidisciplinary supportive care remains the priority.

Treatment of SJS/TEN involves a multidisciplinary approach. This means that your care will require the input from a number of specialties, which may include dermatology, ophthalmology, intensive care, burns, plastics surgery, respiratory medicine, and renal medicine. Other clinicians involved may include dieticians and physiotherapists. You will need intensive skin and mouth care from specialist nurses.

After discharged, what should you do?

- Keep all of your appointments when discharged.
- Skin, mouth, eyes and other areas may continue to be bothersome. It is important that you follow the discharge instructions you are given. This should include advice about moisturisers, eye care and mouth care. The skin will remain sensitive to sunlight for many months, so we recommend covering the skin from bright sunlight, using a sun block (at least SPF 30) on exposed skin, and wearing sunglasses when outdoors.
- Remember you may feel tired for weeks (even months) after you get home. It is very important that you rest but just as important to do as much gentle activity as possible.
- It is normal when recovering from a serious illness to feel low in mood. If this persists or worsens please tell your doctors or specialist nurse, as support with this is available.
- We advise you maintain a healthy life style including a well-balanced diet
- Do not introduce any new medication without a discussion with your doctor (even over-the-counter preparations). We also advise that you do not use any herbal or natural preparations; these agents are not formally regulated and there is no way of knowing their exact constituents.
- If there is an offending drug that triggered SJS/TEN, keep a record and be sure to inform all medical practitioners. We advise wearing a medical alert device, such as a bracelet or pendant with this information.
- In children where infection is the trigger for SJS/TEN, there is a small chance that it can recur, therefore it is important to *seek medical attention promptly* if this happens

For details of source materials used please contact the Clinical Standards Unit (clinicalstandards@bad.org.uk).

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

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