CONDITION

Toxic epidermal necrolysis

Toxic epidermal necrolysis is a severe reaction, usually to medicine, that causes widespread blistering and skin loss.

WHAT IT IS
Severe immune reaction causing widespread skin detachment

BODY SYSTEM
Skin and moist linings of the body

MAIN SYMPTOMS
Painful rash, blisters, skin peeling, mouth or eye sores

WHAT CAUSES IT
Usually an immune reaction to medicine

HOW IT IS DIAGNOSED
Clinical examination and skin biopsy

MAIN TREATMENT
Intensive supportive care and stopping the trigger

CAN IT BE CURED?
Sometimes - the acute reaction may resolve with intensive care

IS IT AN EMERGENCY?
Yes - painful blistering or peeling skin needs emergency care

LONG-TERM OUTLOOK
Many recover; death or lasting complications can occur

Overview

Toxic epidermal necrolysis, or TEN, is a rare but very serious reaction that affects the skin and mucous membranes. Mucous membranes are the moist linings of areas such as the mouth, eyes, nose, genitals, and airways.

In TEN, the immune system causes large numbers of skin cells to die. The top layer of skin then blisters and separates from the tissue underneath. This can lead to extensive areas of raw, exposed skin.

TEN belongs to the same group of reactions as Stevens-Johnson syndrome, often shortened to SJS. Doctors classify them by how much skin has detached:

The loss of the skin barrier can disrupt fluid balance and body temperature. It also increases

the risk of infection and can affect internal organs. TEN therefore requires immediate hospital care, often in an intensive care or specialist burns unit.

- SJS affects less than 10% of the body surface
- SJS-TEN overlap affects 10% to 30%
- TEN affects more than 30%

Symptoms

TEN often begins with symptoms that can resemble a viral illness. These may appear before the skin starts to blister and include fever, tiredness, headache, sore throat, cough, or aching muscles.

Skin pain is an important early feature. The skin may feel unusually tender, burning, or painful before obvious peeling develops. A red, purple, or dusky rash may spread quickly across the face, chest, back, and other areas.

The main signs can include:

Swallowing, eating, urinating, or opening the eyes may become difficult. If the airways are affected, there may be coughing, shortness of breath, or increased mucus.

Symptoms do not always appear all at once. A reaction may continue to progress after the suspected medicine has been stopped.

- Widespread painful or tender skin
- Flat red or dark patches that develop blisters
- Skin that peels away with light pressure
- Raw or crusted sores in the mouth and on the lips
- Red, painful, light-sensitive, or gritty eyes
- Painful sores around the genitals or urinary opening

Causes and risk factors

TEN is usually caused by an abnormal immune reaction to a medicine. The reaction is not the same as a common side effect, and it is not caused by taking too much medicine.

Medicines associated with TEN include certain antiseizure medicines, sulfonamide antibiotics, allopurinol, some anti-inflammatory medicines, and some medicines used to treat infections.

Many other medicines have also been reported as possible triggers.

The reaction most often begins within the first several weeks after starting a responsible medicine. It may happen more quickly if someone is exposed to the same medicine again. However, timing alone cannot prove which medicine caused the reaction.

Infections may occasionally be associated with similar severe skin reactions, particularly in children and younger people. Some infection-related reactions are now classified separately from SJS and TEN. In a proportion of cases, no definite trigger is found.

Certain inherited gene variants can raise the risk from particular medicines. The relevant variants differ between ancestry groups and medicines. Having a risk variant does not mean that TEN will definitely develop, and most people who take medicines linked with TEN never experience it.

A previous episode of SJS or TEN is an important risk factor for another reaction to the same medicine or, in some cases, a closely related medicine.

Diagnosis

Doctors diagnose TEN by examining the skin, measuring the area of detachment, and looking for involvement of the mouth, eyes, genitals, and other mucous membranes.

A detailed medicine history is essential. This includes prescription medicines, over-the-counter products, and medicines that were recently stopped. Doctors compare when each medicine was started with when symptoms appeared.

A skin biopsy is usually performed. A small sample of affected skin is removed after the area is numbed and examined under a microscope. This can show the widespread death of skin cells typical of TEN and help rule out conditions that can look similar.

Blood tests do not confirm TEN, but they help assess fluid balance, blood cell counts, kidney and liver function, and signs of infection. Other tests may be needed if the lungs or additional organs appear to be affected.

The hospital team may use a scoring system to estimate the risk of serious complications. This helps guide monitoring but does not predict exactly what will happen to an individual.

Treatment and management

The first step is to stop the suspected medicine as soon as possible. Medicines that are not essential may also be paused while the cause is investigated. A suspected trigger should not

be restarted simply to test whether it caused the reaction.

Treatment takes place in hospital. Care is often provided by a team that includes dermatology, intensive care, burns, eye, pain, and wound-care specialists.

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

Antibiotics like amoxicillin or doxycycline treat a confirmed or strongly suspected infection. They are not automatically used to prevent infection because unnecessary antibiotics can create additional risks.

An eye specialist should assess eye symptoms early. Treatment may include frequent lubrication and other measures to reduce inflammation and prevent the eyelids from sticking to the eye surface. Severe eye involvement may require a protective tissue covering placed over the eye.

Medicines that alter the immune response may be considered. Options used in specialist centres include corticosteroids like prednisone or hydrocortisone , ciclosporin, intravenous immunoglobulin, and medicines that block a chemical called tumour necrosis factor. Evidence about which treatment works best is still developing. The choice is based on factors such as how quickly the reaction is progressing, other health conditions, and the centre's experience.

- Carefully managed fluids and body salts
- Temperature control and nutritional support
- Pain relief
- Gentle wound care and protective dressings
- Monitoring for infection and organ problems
- Care of the mouth, eyes, and genital area

Complications

Because skin normally prevents fluid loss and blocks germs, extensive detachment can lead to dehydration, abnormal body salt levels, difficulty controlling temperature, and infection. A serious bloodstream infection can occur.

The lungs, liver, kidneys, digestive system, or bone marrow may also be affected. Complications are more likely when a large area of skin is involved or when someone has other major health problems.

Possible longer-term effects include:

Not everyone develops long-term complications. Eye problems can continue or appear after

the skin has healed, so follow-up remains important.

- Dry eyes, light sensitivity, scarring, or changes in vision
- Altered skin colour, dry skin, or unusual sweating
- Hair loss or changes to the nails
- Ongoing mouth discomfort or dental problems
- Genital scarring, pain, or narrowing
- Anxiety, low mood, or post-traumatic stress

Prevention

There is no reliable way to prevent a first episode in everyone. TEN is an unpredictable reaction, and most people who take an associated medicine do not develop it.

Genetic testing can identify increased risk from certain medicine-and-gene combinations. It is useful only in selected situations and does not screen for every possible cause of TEN.

After an episode, preventing repeat exposure is essential. Before leaving hospital, you should receive a clear record of the suspected medicine and any related medicines that may need to be avoided.

Keep this information in your medical and pharmacy records. Carrying a medicine-allergy card or wearing medical identification can help during an emergency. Tell every healthcare professional involved in your care about the reaction before receiving a new prescription.

Do not take the suspected medicine again unless a specialist has established that it was not responsible. Deliberate re-exposure to confirm the cause is unsafe.

Living with it and what to expect

TEN is an acute reaction rather than an illness that usually remains continuously active. Once the reaction has stopped progressing, new skin can grow over exposed areas. Skin healing often takes several weeks, but the time needed differs according to the extent of injury and any complications.

Recovery may continue after discharge. Tiredness, weakness, skin sensitivity, altered colour, and difficulty eating can take time to improve. Nails may shed and later regrow. Some changes fade over months, while others may persist.

Routine follow-up may involve dermatology and eye care. Dental, genital, lung, or mental health

support may be appropriate when those areas have been affected. New or worsening vision symptoms should not wait for a routine appointment.

Many people return to their usual activities, although recovery can be gradual. A written medicine-avoidance plan is a long-term part of care. It should include the suspected trigger, related medicines to avoid, and safer alternatives where these are known.

Experiencing TEN can also be frightening. Disturbed sleep, fear of taking medicines, or upsetting memories are understandable. Psychological support can be included in recovery care.

When to get medical help

Seek emergency medical care now for a painful or rapidly spreading rash with blisters, peeling skin, or sores involving the mouth, eyes, or genitals. This is especially important after starting a medicine within the previous several weeks.

Fever combined with skin pain, facial swelling, blistering, or a spreading dark-red rash also needs emergency assessment. Do not drive yourself if you are severely unwell.

If TEN has already been diagnosed, hospital staff should be told immediately about trouble breathing, worsening confusion, reduced urination, new eye pain, or sudden changes in vision.

After discharge, routine follow-up is used to monitor healing, review the suspected medicine, and check for lasting eye, skin, mouth, or genital problems. Contact your follow-up team sooner for increasing pain, pus, unpleasant wound odour, fever, worsening redness, or new vision symptoms.

Common questions

Is toxic epidermal necrolysis the same as Stevens-Johnson syndrome?

They are different levels of the same type of severe skin reaction. SJS involves a smaller area of detached skin, while TEN involves more than 30% of the body surface. Cases between these levels are called SJS-TEN overlap.

Is TEN contagious?

No. TEN cannot spread through touch, coughing, shared objects, or close contact. It is usually an immune reaction to a medicine, not an infection passed between people.

How quickly does TEN develop?

Early fever, tiredness, or throat and eye symptoms may be followed by a painful rash that

worsens over hours or days. The reaction often occurs during the first several weeks after starting a responsible medicine, but the timing is not identical for everyone.

Will my skin grow back after TEN?

Surviving skin cells can usually produce a new surface layer. Healing often occurs over several weeks. Skin colour, sweating, hair, or nails may remain changed for longer, and some effects can be permanent.

Can I ever take the suspected medicine again?

A medicine thought to have caused TEN is generally avoided permanently because another reaction could be severe and may begin more quickly. Closely related medicines may also need to be avoided. The hospital team should provide a written list specific to the suspected trigger.

Can TEN come back?

It can recur, particularly after exposure to the same medicine or a related one. Good medicine records, pharmacy alerts, and medical identification help reduce this risk. A later rash does not automatically mean that TEN has returned, but blistering, skin pain, or sores on mucous membranes require emergency assessment.

Sources

- Creamer D, Walsh SA, Dziewulski P, et al. "UK guidelines for the management of Stevens-Johnson syndrome/toxic epidermal necrolysis in adults 2016." British Journal of Dermatology . 2016;174(6):1194-1227.
- Seminario-Vidal L, Kroshinsky D, Malachowski SJ, et al. "Society of Dermatology Hospitalists supportive care guidelines for the management of Stevens-Johnson syndrome/toxic epidermal necrolysis in adults." Journal of the American Academy of Dermatology . 2020;82(6):1553-1567.
- Frantz R, Huang S, Are A, Motaparthi K. "Stevens-Johnson syndrome and toxic epidermal necrolysis: a review of diagnosis and management." Medicina . 2021;57(9):895.
- Harr T, French LE. "Toxic epidermal necrolysis and Stevens-Johnson syndrome." Orphanet Journal of Rare Diseases . 2010;5:39.
- National Health Service. "Stevens-Johnson syndrome." NHS health information. Reviewed June 2023.