CONDITION

Non-scarring epidermolysis bullosa

An inherited condition that makes skin blister easily after rubbing or minor injury, usually with little scarring.

WHAT IT IS
Inherited skin fragility causing friction-triggered blisters with little scarring

BODY SYSTEM
Skin, sometimes mouth and other moist linings

MAIN SYMPTOMS
Blisters, skin pain, itching, thickened palms and soles

WHAT CAUSES IT
Inherited changes in skin-strength proteins

HOW IT IS DIAGNOSED
Genetic testing, sometimes specialised skin biopsy

MAIN TREATMENT
Wound care, friction reduction, pain and infection management

CAN IT BE CURED?
No - treatment protects skin and controls symptoms

IS IT AN EMERGENCY?
Sometimes - breathing trouble, severe infection, or dehydration

LONG-TERM OUTLOOK
Mild forms often manageable; severe forms need lifelong specialist care

Overview

Non-scarring epidermolysis bullosa is an inherited condition that makes the skin unusually fragile. Rubbing, pressure, heat, or a minor injury can cause layers of skin to separate and form blisters.

The term most often refers to epidermolysis bullosa simplex , or EBS. In EBS, the separation usually happens within the outer skin layer, called the epidermis. Because the deeper skin is generally not damaged, blisters often heal without permanent scars.

"Non-scarring" does not mean the skin always returns completely to normal. Repeated blistering can leave temporary colour changes, thickened skin, or changes to the nails. Some less common forms can cause skin thinning or limited scarring.

Severity differs widely. Some people only develop blisters on their hands and feet after prolonged activity. Others have widespread blistering from birth and need ongoing specialist care. The condition is not contagious.

Symptoms

Blisters are the main symptom. They may appear after rubbing from shoes, clothing, tools, sports equipment, or everyday movement. Hot weather and sweating can make blistering worse.

Symptoms may include:

Symptoms often begin at birth or during infancy, but milder localised forms may not become clear until a child starts crawling, walking, or taking part in sport.

A baby with a more severe form may develop widespread blisters from normal handling or clothing. Feeding can be difficult if there are mouth blisters. Extensive open skin may also lead to fluid loss.

- Blisters on the hands, feet, knees, elbows, or other pressure areas
- Pain, tenderness, or itching around damaged skin
- Thickened skin on the palms and soles
- Thickened, damaged, or missing fingernails and toenails
- Temporary darker or lighter skin after blisters heal
- Blisters inside the mouth, particularly in more severe forms

Causes and risk factors

Non-scarring epidermolysis bullosa is caused by changes in genes that help skin cells withstand pressure. These genes provide instructions for proteins that hold the skin together.

Many cases involve changes in the KRT5 or KRT14 genes. These genes make keratin proteins, which act like an internal support frame inside cells in the epidermis. Changes in other genes can cause less common forms.

Most EBS is inherited in an autosomal dominant pattern. This means a child can inherit the condition if one parent carries the altered gene. Some forms are autosomal recessive, meaning a child inherits an altered copy from both parents.

A gene change can also appear for the first time in a person, even when there is no known

family history. This is called a new or de novo genetic change.

The condition affects people of any sex or ethnic background. Activity, heat, and friction can trigger blisters, but they do not cause the underlying condition.

Diagnosis

A clinician may suspect epidermolysis bullosa from the pattern of blistering, the age when it began, and any family history. Several types can look alike, so specialist testing is important.

A genetic test can identify the altered gene and often confirm the exact type. This information may help explain likely symptoms and inheritance.

Sometimes a small skin sample, called a biopsy, is taken from the edge of a newly formed blister. Special laboratory methods can show which skin layer has separated and which proteins are missing or reduced. These methods include immunofluorescence mapping and, less often, electron microscopy.

Other tests may check for anaemia, poor nutrition, or infection when symptoms are extensive. Genetic counselling can help you understand test results and what they may mean for relatives or future pregnancies.

Treatment and management

There is currently no cure that corrects the inherited skin fragility. Treatment focuses on preventing avoidable injury, caring for blisters, controlling symptoms, and treating complications.

Skin care usually involves non-stick dressings that protect wounds without tearing nearby skin. Adhesive tape and strongly sticky dressings can damage fragile areas. An epidermolysis bullosa team can demonstrate safer dressing changes and ways to remove dressings with less discomfort.

Blisters are sometimes carefully drained while leaving the blister roof in place as a natural covering. This should be done using the method taught by the specialist team. Removing the roof can expose tender skin and increase fluid loss.

Other management may include:

Bathing can help loosen dressings and clean the skin gently. The water temperature and products used may need adjusting if bathing causes pain or dryness.

Physiotherapy or occupational therapy may help someone stay active, protect vulnerable

areas, and adapt school, work, or daily tasks. Mental health support can also be useful when pain, visible wounds, or time-consuming care affects confidence and relationships.

More severe forms are usually managed by a team that may include dermatology, nursing, pain, nutrition, dentistry, physiotherapy, and genetic specialists. Research into gene, cell, and protein-based treatments is continuing, but availability remains limited.

- Soft, well-fitting shoes and clothing with minimal seams
- Padding for areas exposed to repeated pressure
- Measures to reduce overheating and sweating
- Pain relief before wound care or activities
- Treatments for persistent itching
- Antibiotics like amoxicillin or doxycycline when a bacterial infection is confirmed or strongly suspected
- Foot care for thickened skin, painful cracks, or nail problems
- Nutrition support if mouth pain or extensive wounds affect eating

Complications

Broken skin can become infected. Warning signs include increasing redness, warmth, swelling, pus, unpleasant smell, or pain that is getting worse rather than settling.

Repeated blistering may cause thickened palms and soles, altered nails, or difficulty walking. Pain and itching can disturb sleep and limit physical activity.

Extensive wounds can lead to fluid loss, anaemia, or poor nutrition, especially in babies and people with severe blistering. Mouth blisters may make eating uncomfortable. Dental enamel is usually normal in EBS, although mouth pain can make brushing harder.

Severe generalised forms can occasionally affect breathing or swallowing during infancy. These problems are not typical of localised EBS but need prompt assessment when they occur.

Prevention

The inherited gene change cannot currently be prevented through skin care, diet, or lifestyle. Someone who develops the condition has not caused it.

Many individual blisters can be reduced, although not always avoided. Limiting repeated

rubbing, using suitable footwear, keeping cool, and protecting pressure points may help.

If the specific gene change is known, genetic counselling can explain the chance of passing it on. Testing during pregnancy or testing embryos created through in vitro fertilisation may be available in some settings. These are personal reproductive choices, not requirements.

Living with it and what to expect

The course depends mainly on the genetic type and the extent of blistering. Localised EBS often affects the hands and feet throughout life. Blistering may become more noticeable during warm weather, long walks, sport, or work involving repeated friction.

Some people find symptoms become less severe with age as they learn their triggers and the skin becomes thicker. Others continue to have regular blistering. Thickened skin on the feet can itself become painful and may need specialist care.

People with mild forms generally attend school, work, exercise, travel, and have families. Activities may need practical adjustments rather than complete avoidance. Planning for footwear, dressings, cooling, and rest can make longer days easier.

Generalised forms may improve after infancy, but they can remain demanding. Dressing changes, pain, itching, and medical appointments may take substantial time. Severe forms may affect nutrition, growth, mobility, and emotional wellbeing.

Routine follow-up helps monitor wounds, pain, feet, nails, nutrition, and daily function. A change in the usual blister pattern, slower healing, or repeated infections deserves review even when it is not an emergency.

When to get medical help

Arrange routine medical or specialist advice if:

Seek prompt medical assessment for spreading redness, warmth, swelling, pus, worsening pain, fever, or an unpleasant smell from a wound. These can be signs of infection.

A baby with unexplained or widespread blistering needs urgent medical assessment. Blistering has several possible causes, and early specialist care can protect the skin and manage fluid or feeding problems.

Seek urgent help if mouth or throat blisters make swallowing difficult, if an eye becomes painful or blistered, or if there are signs of dehydration such as very little urine, marked drowsiness, or inability to drink.

Call emergency services for difficulty breathing, severe weakness or confusion, collapse, or signs of a rapidly worsening infection.

- Blisters are becoming more frequent or difficult to manage
- Wounds repeatedly reopen or are healing more slowly than usual
- Pain or itching is disrupting sleep or daily activities
- Thickened skin makes standing or walking difficult
- Eating, growth, or weight is affected
- You want genetic testing or advice about inheritance

Common questions

Is non-scarring epidermolysis bullosa contagious?

No. It is caused by an inherited genetic change and cannot spread through touching, sharing belongings, coughing, or sexual contact.

Will every blister heal without a scar?

Most EBS blisters heal with little or no permanent scarring because the damage is within the outer skin layer. Repeated or infected wounds may leave colour changes, skin thinning, thickening, or occasional scars.

Does epidermolysis bullosa simplex get better with age?

Some forms become less severe, particularly after infancy, but this cannot be promised. Localised hand and foot blistering often continues into adult life and may still flare with heat or friction.

Can I exercise if I get blisters easily?

Many people can exercise after adapting the activity, footwear, clothing, and skin protection. Low-friction activities may be easier. An EB specialist or physiotherapist can help balance skin protection with strength, movement, and general health.

Should I pop a blister?

A large or tense blister may spread under the skin if it remains full. EB teams sometimes advise carefully draining it while preserving the skin covering. Ask the specialist team to show you a safe method rather than tearing or peeling the blister roof.

Can my child inherit it from me?

They may, depending on the gene and inheritance pattern. In a dominant form, each pregnancy

can carry a chance of inheritance even if the affected parent has mild symptoms. Recessive forms work differently. Genetic testing and counselling can clarify the pattern in your family.

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