

# What Is Epidermolysis Bullosa?

## *Fast Facts: An Easy-to-Read Series of Publications for the Public*

Epidermolysis Bullosa (EB) is an illness that causes the skin to be fragile. Because the skin is so fragile, it can be easily injured, causing painful blisters to form. These blisters can cause serious problems if they become infected.

Some people with EB have a mild form of the disease with few blisters. For others, there may be many blisters on the skin. Some people develop blisters inside the body – in places such as the mouth, stomach, esophagus (the tube that allows food to move between the throat and stomach), bladder, and elsewhere.

### **Who Gets Epidermolysis Bullosa?**

Anyone can have EB. Generally, the symptoms first appear in babies or toddlers.

### **What Causes Epidermolysis Bullosa?**

Most cases of EB are hereditary (runs in families).

### **How Is Epidermolysis Bullosa Diagnosed?**

A doctor can identify EB by taking a small sample of skin and looking at it under a microscope.

### **What Are the Symptoms of Epidermolysis Bullosa?**

Skin blisters are the major symptom of EB.

### **How Is Epidermolysis Bullosa Treated?**

If you, your child, or another relative has EB, coping with the symptoms can be difficult. You do not have to handle EB alone. There are doctors, nurses, social workers, clergy members, psychologists, dietitians (people who study food and nutrition), and patient and parent support groups that can help.

#### **Preventing Blisters**

To protect the skin from forming blisters, you can:

- Avoid getting too hot by keeping rooms at an even temperature
- Apply lotion to the skin to reduce friction and keep the skin moist
- Wear soft clothing
- Use sheepskin on car seats and other hard surfaces
- Wear mittens at bedtime to help prevent scratching.

U.S. Department of Health  
and Human Services  
Public Health Service

National Institute of Arthritis  
and Musculoskeletal and  
Skin Diseases  
National Institutes of Health  
1 AMS Circle  
Bethesda, Maryland 20892-3675

Phone: 301-495-4484;  
1-877-22-NIAMS (free of charge)  
TTY: 301-565-2966  
Fax: 301-718-6366  
E-mail: NIAMSInfo@mail.nih.gov  
www.niams.nih.gov



### Treating Blisters

When blisters appear, the goal of care is to:

- Reduce pain or discomfort
- Prevent loss of body fluid
- Promote healing
- Prevent infection.

Your doctor may treat the blisters by:

- Explaining how to safely break a blister in its early stages
- Prescribing a mild painkiller so that changing bandages won't hurt as much
- Recommending special bandages that will help the blisters to heal, lessen the pain, and prevent infection.

### Signs of Infection

Even when blisters are treated properly, infections may develop. Signs of infection are:

- Redness and heat around an open area of skin
- Pus or a yellow discharge
- Crusting on the wound surface
- A red line or streak under the skin that spreads away from the blistered area
- A wound that does not heal
- Fever or chills.

### Treating Infection

If you get an infection, your doctor may treat it with:

- A soaking solution
- An antibiotic ointment
- An oral antibiotic to reduce the growth of bacteria
- A special wound covering (for sores that don't heal).

### Preventing Nutritional Problems

In some people with EB, blisters may appear in the mouth and esophagus, making it hard to chew and swallow. Over time, this may lead to nutritional problems. Because nutrition is so important for proper growth and development, it is important that children with EB eat well.

Steps you can take to help prevent nutritional problems in children with EB include:

- Feed infants using a bottle with a special nipple, an eyedropper, or a syringe.
- When the baby is old enough to take in food, add extra liquid to finely mashed food to make it easier to swallow.

- Give your children soups, milk drinks, mashed potatoes, custards, and puddings.
- Never serve food that is too hot.

Dietitians can help anyone with EB by:

- Providing recipes for food that is nutritious and easy to eat
- Suggesting nutritional supplements
- Recommending diet changes to prevent stomach or intestinal problems.

Surgery

Surgical treatment may be necessary in some forms of EB.

- If your esophagus has narrowed because of scarring, your doctor may suggest surgery to enlarge the esophagus so that food can travel from your mouth to your stomach.
- If you are unable to eat, your doctor may suggest a feeding tube so that food can be delivered directly to your stomach.
- If blisters have caused your fingers or toes to fuse together, your doctor may suggest surgery to separate them.

### What Is the Value of Genetic Counseling?

Genetic counseling can be helpful for people with EB and their families. A genetic counselor can:

- Explain how genes cause EB
- Provide information on the likelihood of passing the genes for EB to children.

### What Research Is Being Conducted on Epidermolysis Bullosa?

Current research on EB focuses on:

- Genes involved in EB
- Ways to correct genes related to EB
- Better ways to heal blister wounds
- Improved bandages for blister wounds.

### For More Information on Epidermolysis Bullosa and Other Related Conditions:

#### **National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**

National Institutes of Health

1 AMS Circle

Bethesda, MD 20892-3675

Phone: 301-495-4484 or

877-22-NIAMS (226-4267) (free of charge)

TTY: 301-565-2966

Fax: 301-718-6366

E-mail: [NIAMSInfo@mail.nih.gov](mailto:NIAMSInfo@mail.nih.gov)

[www.niams.nih.gov](http://www.niams.nih.gov)

The information in this publication was summarized in easy-to-read format from information in a more detailed NIAMS publication. To order the Epidermolysis Bullosa Q&A full-text version, please contact NIAMS using the contact information above. To view the complete text or to order online, visit <http://www.niams.nih.gov>.