



Points To Remember About Epidermolysis Bullosa

- Epidermolysis bullosa is a group of diseases in which the skin is easily injured, causing painful blisters to form. These blisters can cause serious problems if they become infected.
- Some people with the condition have a mild form with few blisters. Others may have many blisters.
- A doctor can identify the disease by taking a small piece of skin and looking at it under a microscope.
- Treatment includes proper skin care to prevent blisters, treating blisters and infections, and a good diet. Surgery may be needed in more severe cases.
- Talk to your doctor about how to treat symptoms when they occur.

What is epidermolysis bullosa?

Epidermolysis bullosa is a group of diseases that cause painful blisters to form on the skin. These blisters can cause serious problems if they become infected.

Some people with the illness have a mild form with few blisters. Others have many blisters on the skin. Some people develop blisters inside the body—in places such as the mouth, the stomach, the tube between the throat and stomach, and the bladder.

There are different forms of epidermolysis bullosa, depending upon where the blistering occurs within the different skin layers.

Skin blisters are the major symptom of epidermolysis bullosa.

Who gets epidermolysis bullosa?

Anyone can have epidermolysis bullosa. Usually symptoms first appear in babies or toddlers.

Is there a test for epidermolysis bullosa?

A doctor can identify epidermolysis bullosa by taking a small piece of skin and looking at it under a microscope.

Other tests can identify defective genes in epidermolysis bullosa patients and their family members.

How is epidermolysis bullosa treated?

There is no cure for epidermolysis bullosa, although there are medicines to help prevent infection and to reduce discomfort. Consult your health care professional about the best options for you.

Goals of treatment include [preventing blisters, caring for blistered skin, treating infection, and treating nutritional problems.](#)

Surgery may be necessary in some cases:

- If the tube from your mouth to stomach has narrowed because of scarring, your doctor may suggest surgery to make it larger.
- If you are unable to eat, your doctor may suggest a feeding tube so that food can go right into your stomach.
- If blisters have caused your fingers or toes to join together, your doctor may suggest surgery to separate them.

Who treats epidermolysis bullosa?

Dermatologists can identify epidermolysis bullosa by taking a small piece of skin and looking at it under a microscope.

A genetic counselor can explain how genes cause the disease, and tell you how likely it is that you will pass the disease to your children.

Dietitians can find recipes for food that is nutritious and easy to eat, and recommend diets to prevent stomach problems, constipation, or diarrhea.

Living with epidermolysis bullosa

Coping with the symptoms of epidermolysis bullosa can be difficult. You do not have to handle

the disease alone. There are doctors, nurses, social workers, clergy members, psychologists, dietitians (people who study food and nutrition), and support groups that can help.

Preventing blisters. There are a few things you can do to protect your skin from blistering. These steps will also help protect your baby's skin during cuddling.

- Avoid getting too hot by keeping rooms at an even temperature.
- Apply lotion to the skin to reduce rubbing 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.

Treating blisters. Talk to your doctor about how to treat blisters when they appear. Steps your doctor might take include:

- Explaining how to safely break a new blister.
- 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.

Treating infection. Infections may develop even when blisters are treated. Signs of infection are:

- Redness and heat around open parts of the skin.
- Pus.
- Crusting on top of the sore.
- A red line or streak under the skin that spreads away from blister.
- A sore that does not heal.
- Fever or chills.

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

- A soaking liquid.
- An antibiotic cream or pill.
- A special covering (for sores that don't heal).

Preventing nutritional problems. In some people with epidermolysis bullosa, blisters may appear in the mouth and in the tube leading from the mouth to the stomach. This makes it hard to chew and swallow and can lead to nutritional problems. Because nutrition is so important for proper growth and development, it is important that children with the disease eat well.

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

- Feed infants using a bottle with a special nipple, an eyedropper, or a syringe.
- 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 by:

- Finding recipes for food that is nutritious and easy to eat.
- Suggesting you take certain vitamins.
- Recommending diet changes to prevent stomach problems, constipation, or diarrhea.

For more info

U.S. Food and Drug Administration

Toll free: 888-INFO-FDA (888-463-6332)

Website: <https://www.fda.gov>

Drugs@FDA at <https://www.accessdata.fda.gov/scripts/cder/daf>. Drugs@FDA is a searchable catalog of FDA-approved drug products.

Centers for Disease Control and Prevention, National Center for Health Statistics

Website: <https://www.cdc.gov/nchs>

The Dystrophic Epidermolysis Bullosa Research Association of America, Inc.

Website: <http://www.debra.org>

National Society of Genetic Counselors

Website: <http://www.nsgc.org>

American Academy of Dermatology

Website: <https://www.aad.org>

If you need more information about available resources in your language or other languages, please visit our webpages below or contact the NIAMS Information Clearinghouse at NIAMSInfo@mail.nih.gov.

- [Asian Language Health Information](#)
- [Spanish Language Health Information](#)