Epidermolysis Bullosa: Parents/Caregivers Guide

What is Epidermolysis Bullosa?

Epidermolysis Bullosa (EB) is a genetic disorder that makes the skin extremely fragile and blister when it's exposed to heat, injury, rubbing, or scratching. The fragile skin is due to an abnormal gene that makes the skin layers not attach together as well.

There are many different types of EB with different levels of severity. EB can range from mild blistering to severe blistering. In the more severe types, there may be blisters, erosions, and scarring inside the body such as in the mouth, esophagus, stomach, intestines, respiratory and genitourinary tracts. Severe cases of EB can also affect the eyes, teeth, and nails.

There are 4 types of EB:

- EB Simplex
- Junctional EB
- Dystrophic EB
- Kindler Syndrome

How is EB treated?

The goal in treatment of EB is to minimize or to ease its complications. Many of the complications of EB can be lessened with early action and care.

The main goals of EB care are:

- Protect the skin from injury.
- Use good wound healing processes and products.
- Prevent infections
- Provide the highest level of nutrition.
- Decrease opportunities for possible joint contractures (a shortened, tight area of the skin, ligament, or tendon).
- Have a strong support system for you and your child.

Different types of EB need different kinds of care:

Milder forms of EB need little or no treatment and some get better as the child gets older. More severe forms of EB often need hours of intensive wound care given by a team of healthcare professionals such as:

- Pediatrician
- Dermatologist (skin doctor)
- Nurse
- Dentist
- Gastrointestinal doctor
- Dietitian/nutritionist
- Plastic surgeon/hand surgeon
- Urologist
- Social worker
- Patient family navigators
- Child life specialist
- Psychologist
- Genetic counselor
- Pain specialist
- Anesthesiologist
- Physical and occupational therapists

How can I keep the skin from blistering?

Heat or rubbing against the skin causes blisters. The amount of rubbing or heat that it takes to cause blisters depends on the type of EB.

- Some children blister only after active exercise, while others blister with rubbing of a seam in the clothing against the skin.
- The main goal of EB care is to lower the chance of getting a new blister.
- Stopping all blisters from happening is impossible but by using these suggestions, you can reduce the amount of blistering.
- Actively think about ways to reduce blistering during daily care.

Care at Home

Clothes

In many forms of EB even slight rubbing from clothes can result in blisters. Dress your child in soft clothing with flat seams to lower the chance of this happening. If flat seams are not available, turn clothing inside out so that the seams are not directly against the skin.

- Fabrics such as soft cottons are the best material for both bedding and clothing.
- Cloth diapers are preferred.
- Loose-fitting and lightweight clothes are most comfortable.
- Always keep in mind that clothing should be easy to put on and take off and should be able to go over the dressings.
- Be especially careful around the head, ears, and armpits when dressing or undressing your child.

Shoes

Shoes can be a challenge for some children with EB. Your child should not wear shoes until they are ready to walk.

- Firm or poorly fitting shoes may cause painful blisters on the feet.
- Using dressings to pad the child's feet can help but it also makes it harder to find shoes that fit the right way over padding.
- When buying shoes, notice where the seams are, make sure the shoes are wide enough to go over extra padding or dressings, and don't rub in any areas.
- Soft slippers, especially those lined with sheep skin, work best.
- Crocs™, Ugg® slippers or Ugg® boots are other great choices. Make sure the slippers or shoes have a wide opening for easy access.

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- Children with severely affected feet often prefer not to wear shoes most of the time and just walk around with extra padding on their feet.

Diapers

- Cloth diapers may be preferred depending on the type of EB, but disposable diapers with Velcro® closure are often more desirable by parents because of their better absorbency.
- With a little extra padding at pressure areas, disposable diapers can work just as well as cloth diapers. You can also cut the elastic leg cuff out of disposable diapers to stop the elastic bands from causing increased blistering of the skin.
- Some parents have used cloth diapers and kept them in place with a disposable diaper.
- Whatever type of diaper you use, it is very important to keep the diaper area as clean and dry as possible to prevent diaper rash.

Car Seats and Bedding

- Sheepskin is an excellent padding material for both car seats and bedding. Both natural and man-made sheepskin work well.
- Foam can also be used to add extra padding under the bedding.
- Cotton or satin sheets should be used over the foam or sheepskin.
- Some children with EB may benefit from a waterbed, air mattress, or a specialty pressure-relieving bed. These beds can help to lower friction and prevent blistering.
- Talk with your child's doctor to see if your child may need a specialty bed.

Helpful Reminders:

Comfort:

- Above all, love your child with all your heart and soul. Never feel that you have failed.
- Do your best to help prevent complications, but also encourage your child to live as normal a life as possible.
- Ask your child's care team about safe ways to hold them so that you can give them the emotional support and closeness they need.

Teach and connect:

- Teach yourself and others the best ways to care for your child.
- Ask other parents of children with EB what works for them. Connecting with others can be a great source of information.

Participate:

- Speak up. You know your child best. What works for one child may not be the best choice for your child. It is okay to question everything about your child's care plan, even if this means questioning your child's doctor.

- Discuss dressing options with your child's doctor or nurse. If allowed, try different types of dressings to determine what works best for your child.
- Keep learning about up-to-date research and ask your doctor if a treatment may be good for your child.

Prevent blisters:

- Never use adhesive or tapes on your child's skin.
- Use soft, non-abrasive material for bedding and clothing. Soft cottons are best. It is important that clothing fits well and that there are no seams or elastic bands to rub against your child's skin. Talk with your child's doctor about how to minimize or prevent blistering from happening.
- Do not lift your child up from under the armpits. Instead, pay attention to where the wounds are and pick them up by supporting their bottom or upper thighs and across the back.

Blister care:

- Drain larger blisters as they happen or reoccur. A sterile needle or blade works best. Drain the fluid from the blister, but do not remove the roof of the blister. Blisters that are not drained will spread out and can cause more pain for your child.

Diaper changes:

- Do not lift your child by the ankle when changing the diaper. Lift by supporting the back and bottom. Cradling small babies on a piece of sheepskin is especially helpful when moving your child from place to place.
- Cloth diapers may be recommended for the more severe forms of EB. Plastic diapers hold in heat and have elastic bands which can cause more blistering.

Body temperature:

- Do not take your child's temperature rectally. Use an ear thermometer (without pulling the ear) or take the temperature from under their armpit. Make sure to teach others caring for your child about the best method to check the temperature.

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