

### How can I support a student with epidermolysis bullosa?

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## Epidermolysis Bullosa

- ✓ Ask the student and their family directly how you can help. Take this opportunity to listen to their individual needs.
- ✓ Meet with parents prior to school starting to learn about the EB student. Remember there are different types of EB and EB patients are affected differently.
- ✓ Provide the opportunity for them to discuss their condition with the class if they wish to do so. They may prefer the teacher provides information to the class. This can allow their peers to ask questions in a productive setting. They may show "What is EB?" video (link on next page).
- ✓ Students may benefit from mental health support if experiencing emotional distress. This should be discussed with the child (depending on age) and their caregivers and refer to mental health support as appropriate.
- ✓ Immediately address any teasing and bullying. Provide education to any students saying harmful things and offer effective support for the affected student.
- ✓ Individuals with EB are at higher risk for bullying and social isolation. We encourage school personnel to proactively identify any bullying concerns and foster an environment of inclusion. We discourage singling out children with EB from their classmates and encourage participation in the same activities as their peers. We encourage staff to learn about EB and correct any misinformation that may be presented by students, caregivers and staff.
- ✓ Recognize their interests and acknowledge their successes in the classroom and in social settings.

### OVERVIEW

Epidermolysis bullosa (EB) is a group of rare genetic skin disorders causing fragile skin. Fragile skin presents as blisters and tears easily. Minimal trauma and friction can lead to blisters and wounds.

There are different types of EB. Some are mild, affecting primarily the hands and feet. Others are severe, affecting the skin of the entire body and internal structures as well. Internal structures that can be affected are the gastrointestinal and urinary tracts.

EB is a chronic disease with no cure. Some mild forms may improve as children get older. The blistering puts affected children at higher risk for infection.



# Epidermolysis Bullosa

## What symptoms does someone with epidermolysis bullosa experience?

**Blisters can be very painful.** Some blisters can heal with scarring that can limit movement and interfere with daily activities. There may also be thickened skin on the palms and soles. This makes the use of hands and standing for long periods difficult. EB can cause blisters inside

the mouth and throat as well which can cause painful swallowing. There may be difficulty passing stool due to blisters near the anus. Blisters can form on the scalp causing scars and hair loss. Wounds may also emit an odor.

Affected individuals may face significant emotional challenges due to their skin disease. They should be supported and referred for mental health support as appropriate.

## What special measures might students with epidermolysis bullosa need?

**Students with EB do not have cognitive changes.** They should be encouraged to perform academically along with their peers.

Occupational therapy consultation is beneficial to ensure that the appropriate accommodations are being made. Students with EB may require supportive seating as sitting for extended periods of time can cause friction and pain.

Individuals with EB may have difficulty writing due to blistering, scarring, and pain of the hands/fingers. They may need additional time to complete written assignments. Modifications, such as the use of tablets, might also be needed.

Individuals with EB may experience pain when walking. Students may benefit from additional time to walk from one place to another. They may also take longer to use the restroom.

Assistance may be required to transport school supplies and/or personal belongings as carrying a backpack may not be possible as this could lead to friction and increased blistering.

Physical activity participation can cause significant blistering. Affected students may need accommodations with indoor activities. They would also benefit from creative ways to keep them involved with outdoor play without physical contact (ex. scorekeeper, referee). Gentle touch and play are okay if the other students are aware and careful. Most EB patients know their limits and will know when to stop activities. Parents can provide guidance on level of activity tolerated.

Students with EB may also have dietary modifications. Some might have restrictions due to scarring in their mouth or feeding tube. They might have special diets or require more time to eat. Others might require feeding by gastric tube. This is something the child's parents will be able to share with you.

Students with EB may have frequent medical appointments which require time away from school. Together with the caregivers and child, the school can provide guidance on how best to keep the child from falling behind.

## Is it contagious?

**No, epidermolysis bullosa is not contagious.** Other students will not get epidermolysis bullosa with physical contact or play.



### SOURCES & ADDITIONAL RESOURCES

#### > "What is EB?" Video

Epidermolysis Bullosa Team at Children's Hospital of Colorado  
<http://www.debra.org/what-is-EB-video>

#### > "Your Welcoming Classroom" Video

Epidermolysis Bullosa Team at Children's Hospital of Colorado  
<https://www.debra.org/classroom-video>

#### > School Resources

Dystrophic Epidermolysis Bullosa Research Association of America (DEBRA of America)  
<http://www.debra.org/school-resources>