

Supporting students with epidermolysis bullosa (EB) at school

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Working together to support students with epidermolysis bullosa (EB)

This guide is designed to:



Help school nurses and educators understand EB



Support safe care at school, focused on protecting the student's skin



Encourage a collaborative partnership between school nurses and the student's caregiver(s)



Reduce stress and uncertainty for both school staff and families

What is epidermolysis bullosa (EB)?

EB is a group of rare genetic conditions that make the skin very fragile. This means that even small bumps, friction, or everyday activities can cause blisters, wounds, and pain. In some cases, EB can also affect other parts of the body, such as the mouth, eyes, or internal organs.

There is currently no cure for EB. Daily care focuses on protecting the skin, preventing injuries, managing wounds, and keeping the student as comfortable as possible. Students living with EB often need gentle handling, individualized support, and clear communication between school staff and the student's caregiver(s) to stay safe throughout the day.

Types of epidermolysis bullosa (EB)

There are 4 main types of EB: EB simplex (EBS), Kindler EB (KEB), junctional EB (JEB), and dystrophic EB (DEB). Each can range from mild with blisters only in certain areas (localized), to more severe forms that affect many parts of the body (generalized).

EB simplex (EBS)

EBS is the mildest and most common type of EB, affecting up to 70% of people with EB. It affects the top layer of the skin.

Localized EBS: Affects mostly the hands and feet, with blisters that may form due to heat, humidity, or friction and usually heal without scarring.

Intermediate EBS: Can cause blistering all over the body. The main areas affected are the hands, feet, and where clothes rub against the body.

Severe EBS: May cause blisters underneath the nails and in the mouth, with blistering often improving during late childhood.

Dystrophic EB (DEB)

DEB is the second most common type of EB, affecting about 25%–50% of people with EB. It affects the middle layer of the skin.

Dominant DEB (DDEB): Causes blistering in areas prone to friction (hands, feet, knees, elbows) that often leads to scarring. The inner linings of the body (like the mouth and throat) are often affected, which can make it difficult to eat or cause constipation.

Recessive DEB (RDEB): One of the most severe forms of EB with widespread blistering, chronic wounds, and scarring. Fingers and toes may fuse together. The inner linings of the body (like the mouth and throat) and the anus are often affected. Blisters in the mouth and throat make eating difficult.

Junctional EB (JEB)

JEB is a rarer type of EB, affecting about 5% of people with EB. It affects the area between the top and middle layers of the skin and can cause severe blistering.

Intermediate JEB: Causes widespread blistering of the skin and inner linings (such as the mouth and throat); the eyes and organs may be affected; tooth enamel may not form properly, leading to fragile teeth and decay.

Severe JEB: Causes widespread blistering of the skin, inner linings of the body (like the mouth and throat), and organs. As it is one of the most serious forms of EB, nearly half of affected patients do not survive beyond the first year of life due to failure to thrive.

Kindler EB (KEB)

KEB is the rarest type, affecting less than 1% of people with EB. It affects all layers of the skin. KEB often causes widespread blistering starting right after birth. Over time, blistering may reduce, but the skin can change in color and texture and become very sensitive to sunlight.

What epidermolysis bullosa (EB) may look like during the school day

Students with EB may present with:



Visible bandages or dressings



Blisters or open wounds



Sensitivity to heat



Difficulty writing (hand involvement)



Fused digits on hands or feet and/or use of a wheelchair (if EB is severe)

Less visible signs may include:

- Pain not outwardly expressed
- Anxiety
- Depression

Core principles for care at school

1

Minimize friction and trauma

- Avoid pulling, rubbing, or forcefully removing wound dressings
- Encourage the student to move slowly and carefully

2

Follow individualized care plans

- The student's caregiver(s) and the healthcare team guide care decisions
- Always follow the student's individualized care plan (Individualized Healthcare Plan [IHP], 504 Plan, and/or Individualized Education Plan [IEP])
- Contact the student's caregiver(s) with any uncertainty

Responding to skin injuries at school

What to do and what to avoid

Do:

- ✓ Stay calm and reassure the student
- ✓ If you need to care for a wound, wear gloves or wash your hands to help maintain hygiene and reduce the risk of infection
- ✓ Follow the student's IHP, 504 Plan, and/or IEP
- ✓ Contact the student's caregiver(s) when necessary

Do NOT:

- ✗ Apply adhesive bandages
- ✗ Apply rolled gauze directly to open wounds
- ✗ Use topical medications (unless directed in the student's care plan)
- ✗ Clean wounds aggressively
- ✗ Apply pressure or friction to the wounds
- ✗ Attempt full wound care unless specifically trained and instructed in the student's care plan

Effective communication with caregivers is essential

When to contact the student's caregiver(s):

- Any injury or bleeding
- Increased pain

Seek further medical attention and contact the student's caregiver(s) if the student:

- Has problems swallowing
- Has problems breathing
- Shows signs of infection, such as warm, painful, or swollen skin; pus or an odor from a sore; and fever or chills

Daily support strategies

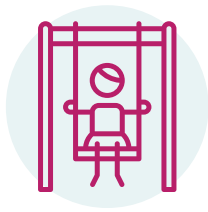
Teachers and school staff can help support students with EB by creating a safe and flexible learning environment. Listening to the student and making small adjustments throughout the day can help reduce the risk of wounds while supporting participation.



Environmental considerations

- Allow extra time between classes
- Allow elevator use (if available) for students with mobility needs
- Allow extra time for eating; consider mouth discomfort or dietary needs
- Reduce friction (e.g., using foam pencil grips or easy-grip scissors)
- Check classroom furniture for sharp edges and remove potential hazards
- Ensure adequate space around desks to prevent bumping or friction
- Avoid heat sources (e.g., heaters, direct sunlight); keep the environment cool
- Consider using padded seating or cushions to minimize skin trauma

Please consult with the student's IHP, 504 Plan, IEP, caregiver(s), and/or occupational therapist on what may be right for the student's needs.



Activity modifications

- Adapt physical education activities with school staff
- Encourage participation with safe, low-impact alternatives
- Allow the student to set their own pace and rest as needed
- Modify or avoid activities involving running, jumping, kneeling, or physical contact
- Provide alternatives for carrying heavy items (e.g., rolling bags, peer/staff assistance)
- Allow flexibility with attendance, lateness, and participation based on the student's condition

Epidermolysis bullosa (EB) care kit

The student's caregiver(s) may supply the school with an EB care kit stocked with essential supplies. This should be stored in the nurses office, along with the student's wound care instructions. Supplies and protocols may vary by student.

An EB care kit may include:



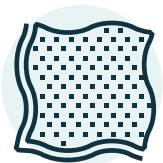
Gloves - for hygiene and infection prevention



Sterile needles or lancets - for lancing blisters, if directed



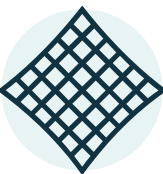
Ointment - to support healing and help prevent infection



Non-adhesive dressings - to protect wounds; may require multiple layers



Gauze rolls - to secure dressings—do NOT apply rolled gauze directly to open wounds



Retainer net dressing - to help keep dressings in place

Emotional and social support



Students with EB may experience:

- Anxiety and depression
- Feeling different from peers
- Social isolation



How school staff can help

- Foster inclusion
- Educate classmates (with caregiver consent)
- Avoid drawing unnecessary attention to the condition
- Support independence where possible

Additional resources

To learn more about supporting students in a school setting, explore these advocacy groups, which offer:

- Clinical guidance
- Support networks for families and professionals
- Additional educational materials to support both daily life and school needs



Scan the QR code or visit debra.org to learn more.



Scan the QR code or visit ebresearch.org to learn more.



Scan the QR code or visit hallieflies.com to learn more.



Scan the QR code or visit debra-international.org to learn more.



Scan the QR code or visit debra-international.org/post/debra-international-youth-council to learn more.

Student information sheet

To be completed by a caregiver and shared with the school nurse.

Please note: This document does not replace or override the student's Individualized Healthcare Plan, 504 Plan, and/or Individualized Education Plan.

Student information

Name: _____

Date of birth: _____

Grade/class: _____

Primary caregiver contact

Name: _____

Phone (primary): _____

Phone (secondary): _____

Email: _____

Diagnosis (if known)

Type of EB: _____

Emergency contacts

Name/relation: _____

Phone: _____

Name/relation: _____

Phone: _____

Name/relation: _____

Phone: _____

Daily care needs (Please describe any routine considerations)

What to do if a blister or wound occurs

(Please specify exactly what you are comfortable with school staff doing)

Specific instructions:

Student information sheet (cont'd)

What NOT to do

Supplies provided to school

- ☐ Dressings
- ☐ Bandages
- ☐ Medications (if applicable)
- ☐ Other: _____

Location of supplies

Pain or comfort considerations

Mobility/physical activity notes

Additional instructions

Caregiver signature _____

Date _____

