

These recommendations are provided in attempts to reduce the risk of trauma to the fragile skin and mucous membranes of patients with EB.

For questions or concerns, contact your institution's dermatology team and visit debra.org/emergency



Scan me to view additional in-depth information or visit debra.org/emergency



EMERGENCY CARE FOR EPIDERMOLYSIS BULLOSA (EB)



Epidermolysis Bullosa (EB) is a rare and complex genetic disorder affecting the skin, oral mucosa, esophagus, eyes, urethra with potential complications in other internal organs.

Extreme Skin Fragility - Avoid adhesives, friction, and rubbing

- May use silicone-based or non-adherent dressings
- Never slide or grab; move by lifting body parts from below
- Remove adhesives from EKG leads or pulse ox (may secure with silicone-based or non-adherent products)
- Apply roll bandaging to pad the extremity before applying blood pressure cuff
- Use adhesive removal spray or emollient to loosen adhesives if inadvertently applied

Anesthesia/ENT Airway Alert

- Consider fiberoptic intubation
- Use well-lubricated laryngoscope w/ smaller than expected ETT if length is appropriate
- Non-invasive airway management preferred. Nasal cannula or emollient on face mask with silicone-based dressing as barrier on skin to reduce trauma
- Prepare for difficult intubation with ENT/ Pulmonary back-up

IV Access

- Dab, do not rub, skin with alcohol pads for labs/IV/antiseptic cleansing
- May require ultrasound for IV placement
- For step-by-step guide for IV access, scan QR code on back of card or visit debra.org/emergency

Lines and Tubes

- Avoid invasive catheters or NG placement if possible
- Clean catch urine samples are preferred
- If urinary drainage is needed, consider smallest effective catheter size with indwelling urinary catheter favored over intermittent catheterization

- If line or tube is needed, insert carefully with extra lubrication

Pre-Op Considerations

- Consider pre-op anemia screening
- Check for recent ECHO and evaluate for risk of cardiac dysfunction

General Recommendations

- **Listen to the family**
- Skin care is patient specific; tolerance varies and tailored interventions may be required
- Generally, silicone-based products are well tolerated
- Routine use of sutures and surgical glue if indicated

My Name:

My EB Type:

My EB Provider:

My EB Provider's Phone Number:
