

*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](http://debra.org/emergency)*



**Scan me to view additional in-depth information or visit [debra.org/emergency](http://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](http://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:**

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**My EB Type:**

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**My EB Provider:**

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**My EB Provider's Phone Number:**

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**After viewing the EB Emergency Wallet Card, please take a moment to fill out the survey below to provide feedback and to help us improve it for future use.**

**Option 1: Enter the Survey Access Code**

1. Go to this web address: <https://redcap.research.cchmc.org/surveys>
2. Then enter this code: 84PEMEHFP

**Option 2: Scan the QR Code**

The QR code below will take you directly to the survey in a web browser.



**Thank you!**