

Epidermolysis Bullosa Travelling Treatment Card

This belongs to...**My Health Care Team is...**

Name	Phone Number	Fax Number
Local Doctor		
EB Doctor		
EB Nurse		
GI Doctor		
Ophthalmologist (eye)		
Dentist (teeth)		
Home Care Coordinator		
Social Worker		

For a complete List of my current medications my pharmacy is:

Name

Phone Number

Fax Number

General dressing removal:

Bathing will facilitate cleansing with the additional advantages of relatively non-traumatic dressing removal and supplemental antibacterial control with antimicrobials (e.g. dilute acetic acid or bleach).

Emergencies:

- Manage patient like all other patients. Ask caregivers or patient about dressing needs or removal
- Assist in necessary adhesive dressing use:
 - Soak any adhesive dressings in water
 - Use petrolatum or mineral oil to try to loosen dressings off skin
 - Use Silicone Medical Adhesive Remover (SMAR)
 - Leave dressing on if caregivers or patient have SMAR to use or can take time to soak dressings slowly
 - References: Debra Canada's EB handbook, Debra UK's adult surgical procedures

Dressings

- Most dressings recommended in this document should be changed every 1–3 days unless: Patient/caregiver preference differs
- Levels of exudate dictate more frequent change as does wound infection or if there is obvious strikethrough.
- It is important to ensure that there are no folds or creases in the dressing that would result in blistering and further damage to the skin.

Categories	Dressings/Other	Body part to use on	Notes
Silicone Medical Adhesive Remover	Niltac spray	Anywhere	To remove adhesive dressing off skin
Hydrogels	Intrasite gel		For wounds with minimal to no exudate Due to hydrating capacity, can provide cooling sensation and may aid in relief of pain, itchy, and discomfort
Contact Layer	Intrasite Conformable Mepitel One Urgotul Urgotul AG Vaseline Gauze Strips		Contact layer to provide non-traumatic removal Reduces pain and trauma during dressing changes. Clings and conforms to all body contours.
Foam / Absorptive layer	AMD disc Mepilex Mepilex Lite Mepilex Border Mepilex Border Lite Mepilex Border AG Mepilex Transfer PolyMem Mepilex AG Telfa		Absorbs wound fluid Provides padding and protection May require secondary dressing Bordered dressings may be too sticky – use with caution Bordered dressings for isolated wounds Poor absorption of highly viscous exudate PolyMem can stimulate increased exudate – protect periwound
Securement	Tubifast securement Surgilast securement Conforming rolled bandage		
Other Equipment	Needles Gauze squares Tapes: Mepitac Tapes: 3M Silicone Blue Tape		
Other therapies for bath	Pool salt Diluted vinegar/acetic acid Diluted bleach		

What is Epidermolysis Bullosa

(ep-ih-dur-MOL-uh-sis buhl-LOE-sah)

Epidermolysis bullosa (EB) is a rare group of life-long skin fragility disorders. All types of EB skin and mucous membranes tend to blister or shear away to minimal daily friction or trauma (such as rubbing or scratching).

Major Risks depending on subtype:

- Increased risk of skin infections
- Intraoral and/or airway blisters
- Uncontrolled pain from their wounds
- Esophageal strictures
- Contractures and scarring
- Increased risk anemia and other vitamin/mineral deficiencies
- Increased risk of squamous cell carcinoma in chronic wounds
- Among many others

General Care Considerations:

- Wash hands with soap and water before dressing changes
- Avoiding trauma/friction by using appropriate clothing, shoes, and if needed use wound dressings indicated in the treatment plan
- Avoid adhesive tapes and dressings, nasogastric tubes (NG), and swabs if possible.
- Minimize taking temperature and blood pressure.
- If blood work is required, the tourniquet should not be placed directly on the skin. Place over clothing or place a Mepilex dressing on the skin first (tourniquet placed on top of dressing)
- Removing the elastic bands from diapers
- Cover open areas if needed
- Use soft sleeping and seating surfaces
- Drain blisters with a sterile needle to prevent the blisters from growing. LEAVE BLISTER ROOF ON. Cover if needed

Inner 1

Inner 2

Inner 3

[illegible]