



CARE OF NEWBORN INFANT WITH SUSPECTED EPIDERMOLYSIS BULLOSA [EB]

- Remove cord clamp and replace with ligature to avoid trauma to surrounding skin.
- Remove identification bracelet & tape to clothing or use a photo as identification.
- Nurse in cot / bassinette on a soft mattress e.g. a Roho cushion using soft bed linen to cover unless incubator required for medical reasons such as prematurity. Avoid overhead heaters as this can cause more blistering.
- Glad Wrap can be used as a temporary dressing while **pain relief** is given and dressing trolley prepared.
- **Blister care:-**
 - Lance and drain all blisters promptly with a sterile needle to limit their spread as EB blisters are not self-limiting and will cause larger wounds. Leave the roof of the blisters intact.
 - Dust small areas with corn flour to dry up the blisters. Larger wounds will need to be dressed using specialised dressings [see below].
- **Wound care:-**
 - If bathing please bath in a 0.9% saline bath [to make this up measure 9 grams of salt to 1 litre of water] otherwise irrigate wounds with warm 0.9 % saline and dress **limb by limb**. Please do not leave the baby naked – cover baby to protect skin particularly the limbs. Leaving the baby fully exposed is likely to cause more damage to the skin
 - Pat skin dry, do not rub.
 - **Open wounds:** Apply primary dressing of silicone mesh i.e. Mepitel [Molnlycke] or Siltex [Bamford] to raw areas. Cover with a secondary dressing of Mepilex Lite / Mepilex [Molnlycke] (depending on amount of exudate) and secure with a cotton tubular bandage i.e. Tubifast [Molnlycke] or Comfifast [Bamford]. Soffban can be used under the tubular bandage for extra protection if required.
 - **Fingers and toes:** dress individually if raw whenever possible to avoid digital fusion.
 - **Open nail beds:** apply primary dressing of Mepitel or Siltex, cover with secondary dressing of Mepilex Lite (as above) and secure with tape [take care to ensure no adhesive tapes come into contact with the skin].
 - If these dressings are not accessible use vaseline gauze / jelonet as a primary dressing and cover with a secondary dressing such as melolin and secure with cotton tubular bandage. [Take care on removing dressings as these can adhere to the wound bed causing more trauma. Always soak off any dressings that have adhered to the wound with warmed 0.9% saline].
 - If Herlitz Junctional EB is suspected - use Intrasite Conformable [Smith & Nephew] as a primary dressing over all wounds and secure with secondary dressings and cotton tubular bandages as above. Change dressing when it begins to dry out.
 - If EB Simplex – Dowling Meara is suspected - the edges of everything may cause blistering. Aquacel [Convatec] is a soft dressing. Apply this as a primary dressing; allow the dressing to

protrude under the cotton tubular bandage so that the edges of the tubular bandage won't cause blistering.

- **Nappy area care:-**
 - Ensure nappies are a good fit. Disposable nappies are fine. Some parents have found Nanny's nappies from the Wholesale Nappy Company, Phone: 0800 846 553 preferable.
 - Cleanse with 50% liquid paraffin, 50% white soft paraffin mix (50/50) [Duoleum].
 - Line nappy with soft liner or soft gauze to prevent friction on skin if required.
 - Cover open lesions with Intrasite Conformable [Smith & Nephew].
 - Application of barrier cream as advised by the EB Nurse Specialist.
- **Feeding:-**
 - Encourage breast feeding if tolerated.
 - For bottle feeding - haberman or pigeon teat & bottle may be better tolerated.
 - Protect lips/teat/nipple. 50/50 [duoleum] or vaseline can be used. Some mother's have found Lansinoh nipple cream preferable.
 - Avoid naso-gastric tube if possible but if essential, use a naso-gastric tube suitable for long-term feeding and secure with Mepitac or Mepiform silicone tape [Molnlycke] or Siltape [Advancis].
- **Handling:-**
 - Handle gently to avoid friction. Avoid sliding your hands under the baby as shearing forces cause damage.
 - Roll baby onto flat hands and arms before lifting (use a roll and lift technique).
 - Lift on soft pad / blanket / cushion.
 - **Do not lift the baby under their arms.**
- **Clothing:-**
 - Turn under-garments inside out to avoid damage from seams and labels.
 - Dress in soft, front fastening baby clothes.
 - Never nurse the baby naked unless essential for intensive care monitoring.
- **Intravenous Lines:-**
 - Use Episil Soft Silicone Film Dressing to secure.
 - Consider SilvaSorb Site Dressing [REM Systems] for anti-microbial cover.
- **For removal of tape without skin stripping:-**
 - Cover with 50% liquid paraffin / 50% white soft paraffin [Duoleum], which will dissolve the adhesive and enable safe removal. Alternatively olive oil or alcohol free adhesive remover wipes can be used if available i.e. Niltac [trio healthcare]
 - If adherent dressings have been applied please do not attempt to remove these whilst they are functional, e.g. securing of an IV cannula. Please contact an EB Nurse Specialist for guidance of removal.

Please order 50% Liquid Paraffin and 50% Soft Paraffin (50/50) [Duoleum] from pharmacy as soon as possible. Please be mindful of the risk of cross contamination. To reduce this risk please decant small amounts using spatula or other clean instrument into a container e.g. a specimen pot and discard daily.

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