MCN for Neonatology
West of Scotland
Neonatal Guideline

Epidermolysis Bullosa (EB) Care of Neonates

This Guideline is applicable to all staff in neonatal units in the West of Scotland. Staff should also refer to relevant drug monographs.

The guideline covers the immediate care of neonates with Epidermolysis Bullosa (EB), or neonates provisionally diagnosed with EB and is based on clinical practice guidelines published in 2024 (Br J Dermatol; 190 (5); 636-656).

Epidermolysis Bullosa (EB) is the commonest of the genetic disorders with skin fragility. Other genetic disorders with skin fragility are peeling skin disorders, erosive disroders, hyperkeratotic disorders and connective tissue disorders.

In EB fragility of the skin and mucous membranes leads to a tendency for the skin to blister when exposed to minimal friction and trauma. EB is commonly sub divided into 4 major groups - simplex, junctional, dystrophic and Kindler syndrome. In severe forms of EB, blisters and wounds are usually present at delivery or result from handling immediately after birth. In milder forms of EB, these will often appear during the neonatal period but can be very extensive. Secondary infection is a primary complication. It is important not to give an exact diagnosis as to subtype without a supportive family history or genetic testing. In the neonatal period blistering can range in severity for all EB subtypes.

Scope of the Guideline

- Neonatal/Paediatrics/Dermatology

Contact details for EB nurses / Dermatologist with specific interest

- Sharon Fisher EB Clinical Nurse Specialist NHS Scotland
  Tel: 07930854944 email: Sharon.Fisher2@nhs.scot
- On Call Paediatric Dermatologist via RCH Switch board 01412010000

Treatment of Skin

- Do not nurse in an incubator unless required for other medical conditions, such as prematurity, as heat and humidity can exacerbate blistering.
- Secure the umbilical cord with a ligature rather than a cord clamp this is to prevent trauma to the umbilical area.
- If a cannula is required, secure with Mepitel Film or Mepitac tape.
- Use emollient on oral or nasal suction catheters and use the lowest effective suction pressure avoiding the sides of the mouth while suctioning oral secretions.
- Use a Silicone Medical Adhesive Remover (SMAR) such as Peel-easy for removal of tapes or dressings without skin stripping enabling safe removal.
- Infant should be nursed on a neonatal mattress(such as Repose mattress)whilst in cot or incubator
  Limbs and vulnerable areas should be protected with suitable dressing material or clothing (if condition permits), a suggestion would be to dress in soft, front fastening baby grow; turn inside out to avoid damage from seams and label. This will help reduce further skin loss from baby movements such as kicking and will protect skin when being handled for general care in cot/incubator and when being lifted out of cot for feeding or contact with parents
- Line the inside of the napkin with a liner (e.g Conticloth)which is larger than new born size nappy ,placed inside nappy and resultingly overlaps at waistband and leg openings preventing friction and subsequent trauma from the edges of the napkin.
- Use a greasy emollient commonly known as 50/50 ointment(50% liquid paraffin/50% white soft paraffin) to cleanse napkin area in preference to water, this aids cleansing without further trauma and will reduce pain.
- Avoid bathing until inter-uterine and birth damage have healed and helps prevent damage from infant being handled naked.

Feeding

- Use Latex Orthodontic feeding teat (commonly available in wards and cleft lip service) to avoid friction to oral mucosa.
- Lubricate feeding teat with teething gel that is suitable for use from birth(e.g Dentinox Infant Gum Gel).

Pain

- Analgesia prior to dressing change

Choices of analgesia should be chosen to reflect the likely degree of discomfort. Choices will include Paracetamol or Morphine. Pleas refer to the WoS Neonatal Pain Guideline for details of neonatal dosages and pain assessment tools.

Recommended and First Choice dressings for neonates with EB - Skin

Dressing type: Polymeric membrane Brand: Polymem
This is the first choice dressing for severe neonatal wounding/critical colonisation/infection. Wear time is as determined by exudates level.
Change when wet to avoid hypothermia.

Recommended and First Choice dressings for neonates with EB – Nappy Area

Dressing type: Hydrogel impregnated gauze Brand: Intrasite Conformable or Hydrosorb
This is for wounds/blisters in nappy areas. Can be used over nappy creams such as Bepanthen or barrier creams such as Proshield. Change daily or when dry. May need a primary contact layer dressing (Urgotul) if severe skin fragility.
Small neonates may be at risk of hypothermia.

Recommended and First Choice dressings for neonates with EB – Between Digits of fingers/toes

Dressing type: Hydrofiber Brand: Aquacel
For very moist wounds where it is difficult to keep dressings in place. Between digits where there is risk of fusion. Change dressing every 3-4 days.
Should not be used if no wound exudates present.

Additional considerations

Genetic diagnosis – Where posible take cord blood sample at delivery for DNA extraction

Cannulation - Use a site where skin is intact, hold limb firmly using soft gauze, compress the limb manually rather than using a tourniquet, to avoid shearing of the skin. Wipe gently with an alcohol swab, do not rub. Cannulae can be fixed using Mepitel Film or Mepitac ® or Siltape ® (the same thing on a roll), fix securely as it does become loose when moist. Soft One ® (cohesive bandage) can also be used over tapes to secure them.
*Splints should be well padded.

Blood Pressure - Place Vaseline gauze with padding around the arm before application of blood pressure cuff. Avoid taking blood pressure more often than necessary.

Pulse Oximetry - This should be done using sensors which can be placed by protecting digit with clingfilm or Adaptic Touch.
If contact poor with using this base protective layer then it may be necessary to apply sensors directly to skin.

ECG Electrodes Hydrogel Electrodes can be used but ensure that a Silicone Medical Adhesive Remover (SMAR) such as Peel-easy is used for safe removal of electrodes without skin stripping

Parental support – In advance of discharge ensure that families are in contact with the EB nursing team. Direct families to EB charity website, www.debra.org.uk where they can access additional information and support.

Product list in EB pack provided for known births

EB New Baby –Advisable items to be available

Skin Care

White Soft Paraffin/Liquid Paraffin BP 50:50 Ointment 500g *nappy area cleansing*
Flaminal Hydro 50g *wounds/blisters*
Peel-Easy Adhesive Remover50ml spray *dressing removal*
Bepanthen Nappy Care Cream 30G *nappy area care*

Wound Care

Polymem Non Adhesive Roll 10cmx61cm *First choice of dressing in Neonates with EB*
or
Urgotul (10cmx10cm/15cmx15cm) *Primary Dressing next to skin*

Kliniderm Lite Foam Silicone without border (10cmx10cm/15cmx15cm) *Secondary Dressing*

Comfifast red line *Retention of dressings*
K-Lite Bandages 5cmx4.5m *Retention of dressings*

HYDROSORB Gel Dressings 10cmx10cm *Nappy wound areas*

Blister Care

Sterile Orange Needles

Guideline Title
WoS_EpidermolysisBullosa_Neonates

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