Newborn Care

FOR EB
Newborn Care
FOR EB

The Newborn with EB .................................................................3
Skin and Wound Care Treatment Steps .......................................4
Missing Skin ..................................................................................6
Pain ..............................................................................................7
Oral Blisters/Lesions .................................................................7
Infection .......................................................................................8
Nutrition .....................................................................................8
Circumcision ...............................................................................9
Diapers ......................................................................................10
Hand Care ................................................................................10
Bedding and Crib Mattresses ..................................................11
Bath and Bathtubs ......................................................................11
Immunizations ...........................................................................12
Home Health Nurses ................................................................12
Prevention and Protection ..............................................................13
Gentle Handling .......................................................................13
Clothing ..................................................................................13
Lubricate the Skin ....................................................................14
Cool Environment ....................................................................14
Mittens .....................................................................................14
Holding the Baby .....................................................................14
Terms and Conditions ................................................................15

For more information about EB:
Visit online: www.ebnurse.org
For EB wound care product questions, contact Bill Cornman:
T 1-800-451-6510 E bcornman@nationalrehab.com
It is impossible to diagnose a newborn with EB by physical exam. While it’s true that the various types have tell-tale signs, at birth and during infancy, there is so much overlap within the clinical presentations that even the most experienced dermatologists will not attempt to diagnose without a biopsy.

Until the diagnosis is confirmed, parents are encouraged to focus on learning to care for their new baby rather than on the various subtypes and possible challenges ahead. It is typical and understandable to feel overwhelmed and out of control and one strategy for dealing with these feelings is to try to learn as much as possible, as quickly as possible. But with an EB newborn, much of what is written about the various types and subtypes will not pertain to your baby. The most productive way to channel this energy and the best way to help your baby is to deal with the immediate necessities for the child’s well-being.

These fall into two categories:
- Skin and wound care
- Nutrition

If possible, delegate a family member or friend to research EB and reach out to support groups.
Skin and Wound Care Treatment Steps

Sterile technique may be maintained in the hospital but it is not the standard at home. Covering affected areas with soothing bandages will make the baby more comfortable and will make it possible for the parents to hold their child.

Vaseline gauze is available in every hospital nursery and should immediately be wrapped around any affected areas. This will provide comfort and help prevent further damage while the staff and parents are figuring out the next step.

No Tape or Adhesives.
Place a LARGE sign over the baby bed to alert all hospital staff that tape and adhesives are not permitted.

Wash hands.
This is the single, most effective way to minimize the spread of infection.

Set out all supplies.
Depending on the child’s condition and what products are available, these will vary, but the essentials are:

- Sterile needles or lancets for draining blisters
- Antibiotic ointment (such as Polysporin)
- Vaseline or Aquaphor
- Contact layer such as Mepitel, Restore, Vaseline Gauze
- Soft, conforming, stretch rolled gauze (2 inch)
- Tubular dressing retainer

Drain blisters.
EB blisters should be drained if they are tense or if they are 1/2 inch in diameter or larger. This is because the fluid inside the blister puts pressure on the surrounding skin, causing the blister to grow. A larger blister takes longer to heal and is at greater risk of becoming infected. It is also more painful than a smaller one. The side of the blister should be punctured using a sterile needle, lancet or manicure scissors. If using a needle, be sure the opening in the blister is large enough that it will not seal and refill. Every effort should be made to leave the blister roof in place, as this improves comfort and healing.
Remove dressings.
Handle one limb at a time. Further skin damage will be minimized if all dressings are not removed at once. The baby will naturally kick and rub the hands or feet and cause bleeding and injury. Also, the wounds are more painful when they are allowed to dry out and when they are exposed to air. Remove the dressings from one limb at a time, provide the care and then apply the dressing to that limb before proceeding to the next. **Do not pull off dressings that are stuck to a wound!** Clothing or bandages that have adhered to a wound must be soaked off. Pulling off a stuck-on bandage will reinjure the wound and cause bleeding and pain. Often, soaking with water or applying a wet compress will be enough to remove a stuck-on bandage. If this is not effective, apply an ointment such as Vaseline or Aquaphor, allow it to sit, and the area will soften and the stuck-on material will release.

Cleanse skin.
The skin and wounds may be cleansed with a mild, non-perfumed product, such as Cetaphil or Dove. Areas with blisters, sores or missing skin may be rinsed or irrigated with a “soapy” solution (Cetaphil or Dove and water) and then with clear water. If necessary, the areas may be patted gently but NOT rubbed or scrubbed.

Apply ointment.
An over the counter antibiotic ointment (Polysporin or Bacitracin) may be applied to affected areas. Some parents prefer to use non-medicated ointments, such as Vaseline or Aquaphor.

Apply dressings.
Next, a non-adherent contact layer should be applied. Examples of such are Mepitel, Restore, Vaseline Gauze or Telfa pads. (See section on Bandaging for more detailed information) Then, the conforming rolled gauze is wrapped around the contact layer and is secured with the tubular dressing retainer.

Every small blister does not require a dressing. Simply applying an ointment may be enough for small, isolated lesions. A blister/erosion/wound should be bandaged if any of the following are present:

- The wound requires protection from further trauma or contact/friction with clothes
- The wound is draining or bleeding
- The wound requires topical treatment for infection
- The wound is painful and a dressing will improve comfort
At first, until it is determined exactly how fragile the newborn’s skin is, daily dressing changes are recommended. New blisters may develop under the dressings and therefore, the skin must be inspected and the blisters drained daily. Depending on the products being used, some may dry out in about 24 hours, further necessitating the need for daily dressing changes (Vaseline Gauze).

Unless there is an obvious problem, such as the bandages becoming soiled from a bowel movement or bleeding under the bandages, more frequent dressing changes are NOT recommended, as the wound bed must be left undisturbed to facilitate healing.

---

**Missing Skin**

**Missing Skin: Congenital Localized Absence of Skin**

Many babies with EB are born with missing skin on the legs, feet, hands, and/or wrists but may occur anywhere on the body. This is referred to by various names:

- CLAS: Congenital localized absence of skin
- Bart’s Syndrome
- Aplasia Cutis or Aplasia Cutis Congenita

Gently cleanse these areas by irrigating with saline or soapy water (mild soap such as Dove). Rinse with clear water. Gently pat dry. Apply Mepitel dressing or Vaseline Gauze to cover the entire denuded area but do not overlap the dressing or the area will become too wet. You may choose to “butter” the Mepitel or Vaseline gauze with Polysporin before applying. Be sure not to coat the edges of the Mepitel dressing with ointment or it will become too wet and it will float all over rather than being stabilized over the wound. Wrap with conforming rolled gauze and secure with a tubular dressing retainer.

**DO NOT USE TAPE!**

These areas remain fragile for extended periods of time, even after they have healed. Because they are typically located on the feet of EB newborns, they are subject to trauma from kicking and movement. They may require protective wrapping for months, or longer.
Pain

EB lesions are painful. The best pain relief is provided by covering the areas with comforting ointments and bandages. Having assistance available and working fast is helpful.

Pre-medicating the baby before dressing changes and baths is a common practice. Using a non-sedating medication (with a physician order), such as acetaminophen or ibuprofen may be helpful. Narcotic medications (such as Morphine) are used when needed but are often avoided because they cause drowsiness and affect the child’s ability to stay awake and take in adequate calories. When such medications are necessary, the parents should try to time the dose so that it will have the least possible impact on feeding.

Oral Blisters/Lesions

In the mouth, a drained blister may look like a white patch, and can sometimes be mistaken for thrush or a fungal infection by those unfamiliar with EB. Most blisters that occur in the mouth will rupture on their own when a child eats or drinks.

When a blister is large or “in the way” and hasn’t drained while the child is sucking or smacking, your medical provider may want you to drain the blister. This should be done while carefully cradling the child in a position that will allow any fluid from the blister to drain out the mouth, not toward the back of the throat. Often, one parent will place the child face down on the lap while the other parent carefully drains or opens the blister, allowing the fluid to drain out of the mouth.

For oral lesions that result from mouth blisters, your provider may prescribe “Magic Mouthwash”, a combination of one part viscous lidocaine, one part liquid diphenhydramine (Benedryl®), and one part liquid aluminum hydroxide/magnesium hydroxide (Maalox®) as a swish then spit preparation: i.e. Swish one teaspoon for one minute and then spit out. This can be used every 4 hours to soothe the pain of these lesions. For children unable to swish and spit, Magic Mouthwash may be applied to the area with a toothette (small sponge on a stick). This must be done cautiously because the viscous lidocaine may numb the gag reflex and allow choking. For this reason, use of Magic mouthwash in infants and very young children is usually not recommended.
Infection

When dealing with fragile newborns, it is extremely important to recognize an infection and treat it promptly.

Many medications, including some topical antibiotics (Silver Sulfadiazine), may not be used on newborns. You MUST consult with and follow the advice of your Primary Care Practitioner if you suspect the EB newborn has an infection.

Signs of infection are:
- Increased exudate (drainage)
- Increased redness
- Increased pain
- Increased swelling
- Increased warmth of skin compared to surrounding area
- Malodorous (unpleasant odor)
- Bleeds easily

Nutrition

Babies with EB require calories sufficient for their growth and development as well as for wound healing. Infants with blisters and lesions in the mouth may have difficulty latching on and maintaining a strong suck. Because nutrition in these babies is so very important, expressed breast milk is often provided rather than actual breast feeding.

If the mother decides to breast feed, the baby’s weight MUST be monitored and a plan to switch to pumping and bottle feeding is essential, should the baby fail to gain weight. Practitioners should help the mother understand that most babies with EB do not breast feed successfully and that bonding will occur if she holds and cuddles the baby during feedings.

Many babies with EB have difficulty sucking from a standard nipple. Cleft palate nipples, such as the SpecialNeeds Feeder (known in the past as the Haberman feeder) http://www.medelabreastfeedingus.com/products/breastfeeding-devices/83/
specialneeds-feeders or the Pigeon feeder (http://www.cleftadvocate.org/PigeonFeederInstructions.pdf) incorporate a valve that facilitates easy delivery of the formula without the need for a vigorous suck. Using a cleft palate feeder, milk may even be squeezed into the baby’s mouth if sucking is still traumatic for the baby.

Infant mouth care may include gentle cleansing with a spongy toothette. Often, the blister roof in the oral mucosa appears white and the pediatrician may mistake this for thrush. Most babies are vigorous eaters, even with blisters in the mouth. As long as the baby is eating well, the blisters should be left alone and the baby will drain them simply by smacking and eating.

If weight gain lags, ceases or if the baby does not begin to gain after a brief period of weight loss (usually occurs within the first week of life), a **Pediatric Registered Dietitian** should **immediately** be consulted. There are many strategies that will help the child gain weight, including fortifying breast milk or formula, providing higher calorie formula or providing formula that is easier for the baby to digest. The Registered Dietitian should work together with the Pediatrician to develop a plan for the child. At the very least, weekly weight checks should be monitored for the infant who is not on an upward growth curve.

Some babies with EB require gastrostomy feeding tubes if they are unable to take in sufficient calories by mouth, which is determined by tracking the child’s height and weight on a growth chart. The pediatrician will keep these charts as part of the baby’s medical record, but it is helpful for parents to track the weight, as well. Parents should be aware of where on the growth chart the baby’s height and weight are plotted and should seek support if the baby is approaching the 10th percentile (or lower).

---

**Circumcision**

It’s OK to circumcise a baby with EB. If the parents were planning to have their son circumcised, the fact that he has EB should not change the decision.

The child will require padding before he is harnessed for the procedure, but it is manageable. Healing from the procedure is reported to be comparable to that of non-EB boys.
Diapers

Diapers often cause blistering and skin shearing around the thighs, on the sides where the diaper ‘leg’ comes together and at the waist. Liberally apply Vaseline or Aquaphor to reduce friction!

Disposable diapers are preferred by many parents because they keep the urine off open wounds on the buttocks. Some disposable diapers have been reported to cause less damage than others due to their cloth-like softness:

- Wal-Mart Brand White Cloud
- Huggies Supremes
- Huggies Ultratirms
- Pampers Swaddlers

Many parents cut the elastic off the legs of disposable diapers to prevent irritation, blistering and skin shearing. Necessity is the mother of invention and EB parents have become proficient at inventing ways to protect their children. Some parents take fleece or a soft fabric and extend it through the leg and waist area to cut down on friction. Others use Johnson & Johnson nursing pads, lube them up with Vaseline or Aquaphor and use them as butt pads, hip pads, etc.

Cloth diapers and cloth diaper covers are preferred by some parents. Two brands that EB parents have used successfully are:

- Fuzi Bunz (www.nurturedfamily.com)
- Happy Heiny’s Pocket diapers (www.happyheinys.com)

Mepilex Lite or Mepilex Transfer may be used to protect the skin, but this is costly, as the dressings will require changing if they get soiled.

---

Hand Care

If the fingers are not significantly blistered or eroded, lubricating the hand with Vaseline or Aquaphor and applying soft, infant mittens seem to provide adequate protection.
The fingers and toes of individuals with Recessive Dystrophic EB are at risk for webbing and curling. During the immediate newborn period, it is almost impossible to individually wrap each finger without causing significant damage to the child. Therefore, the focus should be on wrapping the hand (if needed) with the thumb out and separate from the rest of the hand. When wrapping the hand, it is helpful to add a small, well lubricated ball of Vaseline gauze or other dressing in the palm of the hand. This ensures the fingers will not rub on the base of the palm when the baby makes a fist, and will prevent fingertip blisters. As the child gets older and begins to relax, and when the diagnosis is confirmed, wrapping the fingers individually may do a lot to prevent them from webbing.

---

**Bedding and Crib Mattresses**

No benefit has been reported from using special mattresses. Soft, jersey-knit sheets are found to be soft and comfortable.

Some parents use satin sheets because they are slick and reduce friction. One complaint from the use of satin sheets is that if blood or drainage leaks onto the sheet and is allowed to dry, it will become hard. If the baby rubs against it, a blister may form.

If a wound is present on the back of the scalp, some parents have found it helpful to actually apply a thin layer of Vaseline directly to the sheet in an effort to reduce friction. This is a little harsh on the washing machine, but protecting the baby always seems to take precedence.

---

**Bath and Bathtubs**

When the baby is a newborn, it is easiest to prevent skin damage by following the guidelines outlined above and providing sponge baths as needed. When you are ready to give your baby a bath and depending on how fragile the skin is, you may choose to begin the bath with the dressings in place.

Rather than placing the baby in a typical baby bathtub, you may choose to use a bath sponge. These are available for about $5.00 and will provide padding, slip resistance
and comfort for the parents and the baby. The Munchkin White Hot Infant Bath Cradle is a nice choice because it has a safety dot that turns white when the water is too hot.

Leachco (www.leachco.com) makes some attractive products, as well. The Safer Bather Infant Bath Pad, the Bath and Bumper and the Tuckie Duckie help keep baby safe and secure during bath time.

Bath time is not always fun for kids with EB. Wounds may be painful when exposed to air and water. Damage may occur to intact skin or to wounds during the bath. The parents are usually anxious and frightened. Pre-medicating the baby with acetaminophen before the bath and dressing change will help with pain control. Being well prepared and having an extra person available will make the event less stressful.

---

**Immunizations**

Immunizations should be given on schedule, unless the baby has a fever or other health event and the Pediatrician decides to delay for that reason.

When giving injections to an individual with EB, there should be no vigorous rubbing or massaging of the site and no tape or adhesive bandages placed over the injections site.

---

**Home Health Nurses**

Home Health nurses should be ordered by the physician if the parents need assistance with dressing changes or with understanding the care required.

Home Health nurses are also able to monitor the nutritional status of the infant.
Prevention and Protection

Gentle Handling

Every effort should be made to prevent trauma and friction to the skin.

Babies and young children with EB must not be picked up from under the arms. Rather, they should be lifted by placing one hand behind the head/neck and one hand beneath the bottom. Many parents find it helpful to carry their baby with EB on a pillow, foam pad or sheepskin, which provides extra cushioning and protection.

Clothing

Select clothing that is made of soft fabric, that is loose-fitting without tight elastic bands, and that has easy access for diaper changes and bandage checks.

Pretty smocking and brocade may irritate the skin and cause blisters or skin shearing. The same may be true of appliqués, snaps and zippers. Remove all tags, and if needed, adapt garments by removing the collar and cuffs. For babies with particularly fragile skin, clothes are sometimes worn inside-out so that the seams are on the outside of the clothing, where they will not irritate the skin and cause blistering. When these efforts do not prove to be successful, bandages or soft undergarments (t-shirts, leggings) may be necessary to protect the skin. Special patterns for sewing clothes for newborns and infants with EB are available.
Lubricate the Skin

Apply an ointment such as Vaseline or Aquaphor to intact skin. This will reduce friction and may help prevent some blistering.

Cool Environment

EB skin is often more fragile in warm, humid conditions. It is best to keep a cool environment when possible. Before placing an EB newborn into a car, be aware of the temperature and cool it in advance, if needed.

Mittens

Often the baby will induce facial blisters by scratching or rubbing. Placing mittens or socks over lubricated hands will prevent this and will offer protection, should the baby decide to suck the thumb or fingers. The toes may be cut from larger socks and these may be pulled over the elbows to protect from rubbing and shearing.

Holding the Baby

Sometimes, parents and caregivers are tempted NOT to hold the EB baby very much because they are afraid of damaging the skin and causing blisters.

Some parents even choose not to hold the baby during feedings. Babies with EB need the added comfort and security of being held and touched. The benefit they derive from being held and “loved on” far outweighs any damage that may result from a
blisters. Blisters are a part of the child’s life and cannot be avoided. Parents must figure out a comfortable way to hold their child. Once the baby is properly bandaged and is protected as much as is reasonable, the child should be held and cuddled, the same as any baby. Swaddling the baby will offer added protection. Parents should cut fingernails short, remove large rings and jewelry and wear soft clothing that will not be rough and irritate the baby’s skin.

Terms and Conditions

EBNurse.org is provided for educational and informational purposes only, and is not intended to be a substitute for a health care provider’s consultation. Please consult your own physician or appropriate health care provider about the applicability of any opinions or recommendations with respect to your own symptoms or medical conditions.

The information on EBNurse.org should not be considered complete, nor should it be relied on to suggest a course of treatment for a particular individual. It should not be used in place of a visit, call, consultation or the advice of your physician or other qualified health care provider.

EBNurse.org does not recommend or endorse any specific test, products, or procedures that may be mentioned on the Site. Any opinions expressed on the Site are the opinions of the authors.

EBNurse.org does not assume any liability for the contents of any material provided on the Site. Reliance on any information provided by EBNurse.org, its Health Experts, commentators or other visitors to the site is solely at your own risk.

For more information about EB:

Visit online: www.ebnurse.org
For EB wound care product questions, contact Bill Cornman:
T 1-800-451-6510 E bcornman@nationalrehab.com