

## **Newborn Care**

It is not possible to diagnose a newborn with EB by physical exam. While it's true that the types have telltale signs, there is so much overlap within the clinical presentations during infancy that even 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 baby rather than on the types and subtypes and their potential challenges. It is understandable to feel overwhelmed. One strategy for dealing with the uncertainty is to try to learn as much as possible. But with a newborn, much of what you'll read about EB types will not pertain to your baby, so the most productive way to channel this energy is to care for the child's immediate well-being.

These needs 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.

## **Caring for Newborns**

When caring for your newborn, there are many techniques to follow to lessen the chance of infection and minimize pain at the same time. The most important points to remember when caring for blisters and changing dressings are to maintain a clean, sterile environment and to avoid tapes and adhesives.

Through the use of specialized dressings and wound care products, caregivers can help heal existing wounds and minimize complications, including infection, pain, scarring and contractures.

## **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 parents to hold their child.

Vaseline gauze is available in every hospital nursery and should immediately be wrapped around affected areas. This will provide comfort and help prevent damage while the doctors, nurses and parents determine the next course of action.

## **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 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, Urgotul™, 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 a half-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 for infection. It also is 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. Skin damage will be minimized if all dressings are not removed at once. The baby naturally will kick and rub the hands or feet, causing bleeding and injury. Also, the wounds are more painful when they 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 bandage that is adhering to a wound will exacerbate the wound and cause bleeding and pain. Often, soaking with water or applying a wet compress will be enough to remove a bandage that is stuck. If this is not effective, apply an ointment such as Vaseline or Aquaphor, then allow it to absorb; the area will soften, and the material will release.

### **Cleanse skin**

The skin and wounds can be cleansed with a mild, non-perfumed product, such as Cetaphil or Dove. Areas with blisters, sores or missing skin can be rinsed or irrigated with a soapy solution (Cetaphil or Dove and water) and then with clear water. If necessary, the areas can 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 include Mepitel, Urgotul™, Vaseline Gauze and Telfa pads. (See section about bandaging for more information.) Then, the conforming rolled gauze is wrapped around the contact layer and secured with the tubular dressing retainer. Every small blister does not require a dressing. Simply applying ointment may be enough for small, isolated lesions. A blister, erosion or wound should be bandaged in any of these circumstances:

- 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.

Until it is determined how delicate 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. Some products 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. The wound bed must be left undisturbed to facilitate healing.

### **Missing Skin**

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

- Congenital localized absence of skin (CLAS)
- 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 a contact layer dressing or Vaseline Gauze to cover the entire denuded area, but do not overlap the dressing, or the area will become too moist. You may choose to "butter" the contact layer or Vaseline gauze with Polysporin before applying. Be sure not to coat the edges of the contact layer dressing with ointment, or it will become too moist, preventing it from stabilizing over the wound. Wrap with conforming rolled gauze and secure with a tubular dressing retainer.

Do NOT use tape.

These areas remain delicate for extended periods of time, even after they have healed. Because they typically are 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. Covering the areas with ointments and bandages provides the most effective relief. Having assistance available and working fast is helpful. Medicating the baby before dressing changes and baths is common. Using a non-sedating medication (with a physician's order), such as acetaminophen or ibuprofen, may be helpful. Narcotic medications (such as morphine) are used when needed but often are avoided because they affect the child's ability to stay awake and take in adequate calories. When such medications are necessary, parents should try to time the dose to minimize the impact on feeding.

### **Oral Blisters and Lesions**

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

If a blister is large or "in the way" and fails to drain 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 of 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 (Benadryl®) 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 four 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 with caution, because the viscous lidocaine may numb the gag reflex and allow choking. For this reason, use of Magic Mouthwash in infants and young children usually is not recommended.

## Infection

When dealing with 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 include:

- Increased exudate (drainage)
- Increased redness
- Increased pain
- Increased swelling
- Increased warmth of skin compared with surrounding area
- Malodorous (unpleasant odor)
- Bleeds easily

## Nutrition

Babies with EB require calories sufficient for growth and development as well as for wound healing. Infants with blisters and lesions in their mouths may have difficulty latching on and sucking. Because nutrition in these babies is so important, expressed breast milk often is 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) or the Pigeon Feeder incorporate a valve that facilitates delivery of the formula without the need for vigorous sucking. Using a cleft palate feeder, milk may even be squeezed into the baby's mouth if sucking is traumatic.

Infant mouth care may include gentle cleansing with a spongy toothette. Often, the blister roof in the oral mucosa appears white, and a pediatrician may mistake it for thrush. Most babies are vigorous eaters, even with blisters in their mouths. 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 or 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 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 dietitian should work with the pediatrician to develop a plan. At the very least, weekly weight checks should be conducted for an 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, an EB diagnosis 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 away from wounds on the buttocks. Some disposable diapers have been reported to cause less damage than others because of their cloth-like softness:

- Huggies Supremes
- Huggies Ultratrim
- Pampers Swaddlers

Many parents cut the elastic off the legs of disposable diapers to prevent irritation, blistering and skin shearing. Some parents take fleece or a soft fabric and extend it through the leg and waist area to reduce friction. Others use Johnson & Johnson nursing pads, lubricate them 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.fuzzibunz.com](http://www.fuzzibunz.com))
- Happy Heiny's pocket diapers [www.amazon.com](http://www.amazon.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 seems 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. 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. This ensures the fingers will not rub 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 help prevent webbing.

### **Bedding And Cribs**

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 about satin sheets is that if blood or drainage becomes hard upon drying on the sheet; thus, if the baby rubs against it, a blister may form.

If there is a wound on the back of the scalp, some parents have found it helpful to apply a thin layer of Vaseline to the sheet in an effort to reduce friction. This practice can be harsh on the washing machine, but protecting the baby always takes precedence.

### **Bath and Bathtubs**

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

Rather than placing the baby in a conventional bathtub, you may choose to use a bathtub cushion. These are available for about \$5 and will provide padding, slip resistance and comfort for parents and the baby. The [Munchkin Safety Baby Bath Cradle](#) features a safety dot that turns white when the water is too hot.

[Leachco, Inc.](#) makes products such as the Safer Bather Infant Bath Pad, the Bath 'N Bumper and the Tuckie Duckie to help keep babies safe and secure.

Bath time can be difficult 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. Parents usually are anxious and frightened. Medicating the baby with acetaminophen before the bath and dressing change will help control pain. Being well-prepared and having someone to help will make it less stressful.

### **Immunizations**

Immunizations should be given on schedule, unless the baby has a fever or other health event and the pediatrician decides a delay is necessary. When giving injections to an individual with EB, there should be no vigorous rubbing or massaging of the injection site and no tape or adhesive bandages placed over the site.

### **Home Health Nurses**

Home health nurses should be ordered by the physician if the parents need assistance with dressing changes or with understanding how to provide care. Home health nurses also can monitor the nutritional status of the infant.

### **Prevention and Protection**

Newborns with EB require a gentle touch, a cool environment and soft, loose-fitting clothing. These tips are among the many guidelines that may help prevent blisters from worsening and protect their already fragile skin.

Through the use of specialized dressings and wound care products, caregivers can help prevent new blisters and erosions from forming and minimize complications, including infection, pain, scarring and contractures.

### **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 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 collars and cuffs. For babies with particularly delicate skin, clothes sometimes are worn inside-out so that the seams are on the outside. When these efforts prove insufficient, bandages or soft undergarments (t-shirts, leggings) may be necessary to protect the skin.

### **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 often is more prone to damage in warm, humid conditions. It is best to keep a cool environment when possible. Before placing an EB newborn in 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 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 against rubbing and shearing.

### **Holding the Baby**

Sometimes, parents and caregivers are adverse to holding an EB baby 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 of being held far outweighs damage that may result from a blister. Blisters are a part of the child's life and cannot be avoided.

Parents must determine a comfortable way to hold their child. After the baby is properly bandaged and 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 their own fingernails short, remove large rings and jewelry, and wear soft clothing that will not irritate the baby's skin.