



Caring for the Newborn Baby with Epidermolysis Bullosa (EB)



This booklet is full of helpful tips to help you care for your infant when you return home from the hospital. It is a guide to assist with the many areas of care management for your new baby.

Providing care requires a balance of maintaining skin integrity, nutritional support and avoiding potential complications. You will learn what works best for you and your baby.



Right Care. Right Time. Right Place... at home.



Skin Cleansing

Skin cleansing can be a sensitive issue. To clean the skin, including the diaper area, use a soft cloth moistened with tepid water and a mild soap.

To reduce skin movement, pat the area softly, rather than rubbing. Rubbing of the skin can increase friction and skin warmth, which can lead to blister development.

Make sure to dry the cleansed area completely using the patting method. Moist skin can lead to growth of bacteria and cause skin infections.

Bathing

Cleansing of the skin and frequent dressing changes can help reduce infections with the EB patient. Unfortunately, this process can be painful and unpleasant. Studies have shown that saltwater baths reduce the discomfort associated with bathing and the incidence of infection can be reduced.¹

Salt is safe for use in the bathwater of babies and infants. Add 5 teaspoons of salt (table salt may be used) to each gallon of bath water.²

Immersing the baby in comforting bath water prior to removing resistant dressings allows dressings to be easily removed, thus decreasing pain and anxiety for the baby.

Tepid to slightly warm water is recommended. The frequency of bathing will need to be adapted to each baby individually.

Infection Prevention/Management

For caregivers, hand washing is the best initial defense against infection. Always make sure to wash hands thoroughly before and between dressing and/or diaper changes (see Handwashing Diagram below).

Bleach (0.1%; generally not recommended for children under 1 year), acetic acid (0.25%-1.0%) and saltwater baths (0.08%-1.1%) have also been proven to be effective in reducing surface wound bacteria, which should result in less wound drainage.³

Over the counter antibiotic ointments may be prescribed by your provider if there is a suspected infection at a wound area. These should only be used for short periods of time and rotated every 2-6 weeks to prevent resistance and sensitization.⁴

Bring any areas of concern to the attention of your healthcare provider.

Antibiotics (whether put on the skin, taken by mouth or administered in the vein) would be ordered and managed by your healthcare provider.

1
Wet hands with water.



2
Apply handsoap & lather for at least 20 sec.



3
Rinse both sides of hands with water.



4
Dry hands and shut off faucet with a towel.





Blister Management

Blister formation is the classic presentation of EB. Once the blister has formed, the fluid in the space begins to put pressure on the tissues. As the blister grows, the pressure in the space increases. The most important thing to do is “relieve the pressure” so the pressure in the area can return to normal, the layers of skin will reunite, and the healing process can begin.

Newly formed blisters should be punctured with a sterile needle or lancet to avoid an increase in blister size. Gentle drainage of the fluid from the blister decreases pressure and encourages healing. Leaving the skin covering intact provides a protective barrier against infection.

Once the blister is punctured, it is recommended the area be dressed with a non-sticky silicon dressing* and some topical antibiotic ointment (when infection is present as prescribed by a healthcare provider) or plain petroleum jelly (when no infection is present) over the area. This helps promote a moist healing environment, which is the best for wound healing. Adding an additional absorptive dressing will collect any additional drainage. Applying a tube-type gauze dressing will secure the dressings without the need for tape.

Wound Dressing Management**

Remember to wash your hands before any dressing changes!

It is recommended that bandages be removed and changed once per day initially to allow inspection of the skin and evaluation of new blister formations.

Before you begin the dressing change regimen, have all supplies prepared and ready for use.

- *The first layer of dressing is a non-sticky layer* placed directly on the ointment in contact with the wound. These dressings provide the first layer of protection to the wound.*
- *The second layer of dressing is the absorbent layer, which will draw and contain drainage from the wound while protecting the intact skin around the wound from moisture damage.*
- *The final layer will either be a type of roll gauze or a tube dressing to secure the dressing layers.*

For blisters in the diaper area, dressings with petrolatum or hydrogel-based gauze can be effective and must be changed with each diaper change.⁵

To protect fingers and toes, gloves and cotton socks can be used. Tubular bandages can be used to keep dressings on limbs or in the correct position.

Dressings/clothing that stick to the wounds may produce new and more extensive blisters. Soak dressings off with tepid water, which can be diluted with liquid soap or saline until it can be removed with ease.

In order to keep the baby’s core temperature from dropping, make sure to cover any wet exposed skin with a dry cloth while preparing to dress the wounds.

*For more specific information, please email WOCNconsult@ccsmed.com.

**Follow the wound care regimen outlined in the “Home Care Plan for Baby” per the hospital discharge plan.



Dressing Supplies

You should have a wound care dressing change Plan of Care written by the healthcare provider upon discharge from the hospital.

Supplies may be itemized on the Plan of Care. If there are questions regarding this, contact your dressing supplier or your healthcare provider's office.

Clothing

Dress in clothing "inside out" so seams, zippers and buttons are on the outside.

It may be helpful to sew foam pads into lining of clothing.

Avoid tight-fitting clothes and shoes that can cause increased heat and pressure to skin. Loose-fitting objects are better.

There are seamless, antimicrobial and/or silk specialty garments available, which are very therapeutic and non-traumatic to the skin.*

Gloves are also available for blisters of the hands that require dressings and finger separation.

Shoes should be comfortable, pressure-free and fit well over dressings. Socks are a nice alternative to shoes for infants, as they have not yet begun to crawl or walk.

Baby's Environment

Avoid warm, moist environments. Increased heat and moisture may encourage blister formation. Air conditioning or cooler environments are recommended.

Do not overdress baby, as this may lead to overheating and encourage increased blistering.

For bedding and car seats, sheepskin is an excellent padding material. Egg crate foam or other foam materials can be used as well. These materials will reduce friction. Silk, satin or soft cotton sheets should be used over the foam or sheepskin.

Handling your Baby

Skin separation can occur when lifting an infant under the arms or the ankles. Avoid lifting under the arms or ankles by lifting from the buttocks and back of neck and head. You can roll the baby to one side, place your hands under the head and buttocks, roll back and then lift.

Placing the baby on a sheepskin or foam pad while handling can provide a softer overall environment, reducing the possibility of trauma while feeding or holding.

Learning how to hold your baby will strengthen bonding and provide the essential emotional support and nurturing the infant needs.

**For more specific information, please email WOCNconsult@ccsmed.com.*



Nutrition

Nutrition is generally a very important growth marker for children, but it is especially important for those with EB.

Blistering in the newborn period may produce fluid and protein loss that should be monitored closely.

Regular visits to the Pediatrician to monitor weight and height is important to properly monitor growth.

Breastfeeding is definitely an option for your baby. If sucking at the breast is challenging, breast pumps can be used to express breastmilk and feed the baby with conventional bottles.

Commercially-purchased nipples can be boiled in hot water to soften. Apply petroleum jelly to the lip of the baby and against the mother's breast to decrease friction caused by sucking during breastfeeding.

Sucking may be impaired due to blisters in the mouth. There are special nipples* available, which are activated by tongue and gum pressure, imitating the mechanics involved in breastfeeding.

Oral blisters can look white, like oral yeast (fungal infection). Oral care for your baby can be performed with a soft, moistened toothette (soft applicator with foam-tipped end) through gentle swabbing of the mouth. Spontaneous rupture of mouth blisters may occur during these procedures.

A Registered Dietitian may be a part of the multi-disciplinary care team managing the health plan for your infant. Keeping in close contact with this resource will be key in understanding what the main steps are for your baby's daily feeding plan.

Supplemental formulas may be required to provide your baby with the essential nutrients and calories to maintain normal growth. Your Pediatrician, Registered Dietitian and multi-disciplinary care team will be managing this process with you.

Skin Management/Maintenance

Cleanse skin daily using very mild soap, and apply white petroleum jelly to moisturize skin and reduce surface friction forces.

Daily moisturizing of the skin is very important to reduce blistering, pain and itching.

Ointments may be applied to wounds to promote healing and reduce the incidence of scarring.

Moisturizers containing sodium lauryl sulphate should be avoided, as this can irritate skin and encourage skin damage.⁶

Avoid using highly perfumed products on skin.

Use laundry products formulated for sensitive skin.

*For more specific information, please email WOCNconsult@ccsmed.com.



Diapering

There are many diapering options to consider using either cloth or disposable diapers. For more information on diapering options, visit <http://www.debra.org/dailylivingresources#diapers>.⁷

Keep in mind that blistering can occur from the plastic rubbing in a disposable diaper. There are several adaptations that can be made to disposable diapers to avoid increased blistering.

- *Cut the elastic at the legs to allow more room and less rubbing.*
- *Place a piece of silicone dressing at each groin site to absorb the effects of the diaper edge.*

Pain Management

When the baby is very young, they will not be aware of their care schedule like they will as they age. Developing a dressing change schedule routine will become more obvious as things begin to fall into place.

Medicating with prescribed pain medication may be helpful 30 minutes before a dressing change.

If you notice certain dressings are more difficult to remove, soak the dressings until they remove with ease.

The area where dressing changes will take place should be somewhere other than where the baby rests, is nursed or caressed. This provides the baby with a "safe" place without the potential for discomfort.

The use of soft music, subdued lighting and rocking also provides a source of comfort.

Vaccinations

Childhood immunizations are recommended for infants with EB.⁸

To better understand immunizations, speak with your Pediatrician to make the right choice for your baby.

Circumcision

The American Academy of Pediatrics states in its current policy statement that "evidence indicates the health benefits of newborn male circumcision outweigh the risks and the procedure's benefits justify access to families who choose it."⁹

The decision to have circumcision performed ultimately resides with the parents. Speak with your Pediatrician to determine what is best for your baby.



Resources for Caregivers

Managing your baby at home can seem overwhelming at times. Make sure you have the resource numbers you need.

- **Your Pediatrician and Other Healthcare Providers** - Your child's healthcare provider is the "first line" of medical direction and advice for your baby's care. Make sure to have the office phone number easily accessible in your home. Posting routinely-called numbers on the refrigerator, for example, is a main area in the house where it is easy to quickly locate important numbers.
- **EB Specialty Dressings Provider** - CCS Medical carries a complete line of products specific to EB. **1.800.690.1255** or ccsmed.com
- **Home Health Nursing Services** - If you feel it is appropriate, ask your Pediatrician to order Home Health services for your child. Request a service that specializes in pediatric cases, which can really make a difference in the care provided!
- **Insurance Provider RN Case Manager** - Many insurance companies have Medical Case Managers for complex medical patients that follow the patient's care. These Case Managers can be very helpful advocates for your child.
- **debra.org** - The Dystrophic Epidermolysis Bullosa Research Association of America (debra of America) is the only U.S. nonprofit providing all-inclusive support to the EB Community, through funding research for a cure and by providing free programs and services for those with EB. This website has numerous resources ranging from education about the various types of EB to family support group links.
- **Family Members/Caregiver Support Members** - Post phone numbers of people within your "care network" in a highly visible location of your home for quick access.



For more information about CCS Medical's EB program, call today!



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Footnotes and References

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