

WOUND CARE/DRESSING CHANGE EBS generalized severe

1. Introduction

Even with the best care and the gentlest dealing with a child or an adult with EB, the formation of blisters on the sensitive skin cannot be avoided. Blisters and sores are part of the lives of all people living with EB - but in highly varying degrees. As painful open sores are and represent a portal of entry for germs that can cause inflammation, good skin care is one of the most important things you have to learn to deal with EB. Wound care for the type EBS generalized severe differs in some respects from other forms of EB. The need and the intensity of treatment may thus vary from day to day and there are many different materials (dressings, ointments, aids) that can be applied to adapt the treatment to daily life, work and social conditions. This section will possibly help you find a sensible, painless and also viable wound care for your particular situation.



Important points in a nutshell

- **For EBS generalized severe dressings should be used as seldom as possible!**
- **Preparation: A good preparation of the dressing-station with all the necessary materials and an available place for the disposal of the old dressing material shortens the actual dressing change process.**
- **Hand disinfection: Should always be carried out by all persons involved in dressing changes. Removal of the old dressings: Can be simplified by soaking them in the bathtub or with moistened towels.**
- **Assessment of the wounds and making decisions: Open larger blisters, remove exudates and clean wounds, treat infected wounds.**
- **Apply new dressings: Generally a mesh dressing, then compression dressing and lasting securement.**
- **Picking up and cleaning the dressing-station.**

2. General information

Even with the best care and the gentlest dealing with a child or an adult with EB, the formation of blisters on the sensitive skin cannot be avoided. Blisters and sores are part of the lives of all people living with EB - but in highly varying degrees. As painful open sores are and represent a portal of entry for germs that can cause inflammation, good skin care is one of the most important things you have to learn to deal with EB. Wound care for the type EBS generalized severe differs in some respects from other forms of EB. The need and the intensity of treatment may thus vary from day to day and there are many different materials (dressings, ointments, aids) that can be applied to adapt the treatment to daily life, work and social conditions. This section will possibly help you find a sensible, painless and also viable wound care for your particular situation.

With EBS generalized severe, there are some characteristics to which we would like to address briefly.

Many of those affected with EBS generalized severe have found that they usually get more blisters and sores under their bandages, as in the surrounding areas of the skin. The dressings seem to create a mechanism that stimulates the formation of blisters in this form, rather than prevent it. Why this happens is not yet clear. This is a question that we might be able to answer someday with research. It can in any case be assumed that with this form of EB, the skin temperature plays a special role. But what role that is, is still unclear because we have also observed in people with EBS generalized severe: In febrile infections a significant reduction of blister formation often results and it persists for some time after the resolution of infection. A "normal" blistering then again returns. Currently, there is still no way to use these observations in some way for therapy.

Whatever the reason is: The observation that often more blisters develop in EBS generalized severe under the dressings, has led one to apply dressings as seldom as possible for this form of EB. This does not mean however, that in general no dressings are necessary. Even with EBS generalized severe there are large wound areas, inflamed wounds or special situations. Then the way in which the dressings must be applied, is no different from the other forms.

1. Preparation (dressing station, provision of dressing material, disposal receptacle)

Dressing Changing Area:

In the dressing station area a pleasant warm temperature should prevail and - if the bandages are changed in the tub (more on that later) during a bath - the bathroom should also be kept warm.

When the room temperature is too low, the open sores may cool down very quickly, which causes pain! If it is possible and desirable, distracting measures can be prepared for prolonged dressing changes.

Preparation of Dressing Material:

To make the time as short as possible between removing the old and the application of new dressings, it is advisable to prepare all the materials that are needed in advance. The packaging of the dressing materials should be opened, a waste container provided, scissors, sterile needle, etc. laid ready to hand. Depending on how many wounds you need to be care for will determine how much time is needed to complete the dressings. Some dressings must be cut into the appropriate shape with scissors; this can also be prepared for ahead of time. With time, you will be able to estimate how much you'll need of each cream, ointment, dressing, etc.

Disposal:

You should already think about the fact that a large amount of waste will possibly be generated from the old dressings. These old dressings should not come into contact with the fresh dressing material. Provide a container into which you can throw the removed dressings right away. A simple open bucket with a trash bag lining works well for this. The container just needs to be large enough to accommodate the material produced from the entire dressing change.

2. Hand Disinfection

Hand disinfection is carried out before each dressing change by all persons that will be involved. This is the most important measure to prevent transmission of pathogens and thus to avoid infection (inflammation) of the open wound areas!

Hand disinfection is basically very simple, but is often still done wrong – this means it is ineffective. Please ask well trained staff to show you the right way to disinfect your hands.

Here is a brief guide for proper hand disinfection:

- If you wear any jewelry on your hands (ring, bracelet, and watch), then remove it.
- Apply a hand sanitizer liberally into the dry palm of your hand, spread it onto both hands, including between your fingers, fingertips, thumbs and wrists.
- Rub it onto the palms.
- Rub your palms on the backs of both hands.
- With your fingers spread, rub the sanitizer between the fingers (which works best when you place one palm on one hand).
- Rub the exterior side of the finger in the opposite palm.
- The thumbs should be successively rubbed in circles in the closed palm of the other hand.
- Finally - rubbing of the fingers closed together in the palm of the other hand in a circular motion.
- Completed hand disinfection is only finished when the disinfectant that you use is completely absorbed into the skin. This usually takes about one to two minutes. You have to perform the circular motion described until the disinfectant is absorbed.

3. Removing the old Dressings

The next step is the loosening of old dressings as gentle as possible. This can be done differently, depending on the condition of the wound and type of dressing material used. Some dressings are easy to gently pull off, while others are stuck to the underlying wound, e.g. because of dried blood or wound exudates on the wound.

Never loosen the stuck dressings with force, because it leads to pain for the patient. In addition you could tear the wound open again or make the size of the wound larger. It is best to soak the areas that are stuck first; the easiest way to do this is with water (bath, shower, steam room, wet swabs/dressings). If necessary leave

remaining dressing in place if no infection is suspected and wait a few days until the dressing itself loosens from the wound. Be sure to apply a particularly abundant amount of ointment over this area or on the wound dressing/swabs by the next dressing change to help try to loosen the old bandage and prevent further sticking from wound exudates.

If by chance an adhesive patch was applied to the skin for any reason, you can try to remove it with Niltac[®] spray (from Trio Healthcare - available in pharmacies). Application of this spray according to the instructions dissolves the adhesive bandage and enables a careful removal of the patch. Otherwise, try to soften the adhesive with water (e.g. in the bath or with a damp cloth). If both ways do not work leave the adhesive bandage on the skin until it comes off by itself.

It is advisable to remove the bandages only during bathing or showering because the soaked bandages can be easily peeled away from the skin and wounds. Thus, the dressing change is less painful and has less risk for further injury. Some people prefer to remove the bandages before bathing. This way is also possible and the decision is ultimately left to the parties concerned. The dressing change then takes longer and adhesive dressings are harder to remove.

A few Words about Bathing and Showering:

We are often asked if bathing or showering is better for people with EB. This cannot be answered in general as it depends on your personal situation and especially in regards to your personal preferences. Basically, both are possible. There is a third possibility: A steam shower – this is also a way to soak off the dressings. Several questions must be answered first: for example whether there is a bathtub in your bathroom, if a soft shower spray on the skin feels pleasant or whether the installation of a steam shower is even possible.

When you have a bathtub, then we recommend that you take a bath every other day during the dressing change. But nothing speaks against a bath only once a week, when bathing is perceived as very stressful by the affected person, or if the person concerned is suffering from a cold. Daily bathing is also possible if it is comfortable for the person concerned and dressing changes need to be performed daily. Use plenty of rather lukewarm water because too warm or even hot water burns the wounds. Cold water is also not appropriate. On one hand it is not pleasant

and on the other hand it can cool off the wounds. This can lead to severe pain. The temperature must be perceived as pleasant by the person concerned. Certainly you will quickly find the most suitable temperature for bathing. In the case of numerous and/or infected wounds full baths with disinfectant are recommended adding bacteria-reducing additives. The reduction of germs has a positive effect on wound healing. Other additives (e.g. moisturizing) can be useful. You might want to seek advice from knowledgeable people.

If you prefer the shower or you do not have a bath, then of course you can soften the dressings in a shower. When showering, make sure that the shower spray is gentle. One can imagine that a hard jet stream of water on the vulnerable and injured EB skin can have very painful effects. A soft temperature regulated shower head can be perceived by many affected as very pleasant. If a shower is used for the loosening of dressings, it serves the purpose as well as a full bath.

After bathing or showering the skin is gently patted or dried with a soft towel or cloth diaper. Since it will now take a while until all dressings are applied, the room temperature is important. Open wounds cool very quickly which causes pain. In a room with a warmer temperature you have a bit more time for dressing changes.

4. Assessment of wounds and treatment decisions

Once the bandages are removed, you need to look at the skin to see what now needs to be cared for. In EBS generalized severe only very small blisters usually occur, which are often in small groups. These smaller blisters should not be opened, yet larger blisters should be opened with a thicker needle or a suitable pair of scissors.

All larger blisters should be pierced with a "thick" sterile needle (18-gauge = pink), with a lancet or a suitable pair of scissors. This allows the contents in the blister to be emptied. You should gently express the contents of the blister, so that the pressure exerted on the sore spot is relieved. Moreover, this prevents the blister from increasing in size. The blisters are not self-limiting and can spread, if they are not opened.

The blister roof serves as a natural protection against germs, try not to injure it and leave it over the wound. If this not possible, it can also be removed. The smaller the blister is that you pierce; the remaining wound will also be small. If the opening in

the roof of the blister is not large enough (e.g. by using a fine needle), the blister can again fill up quickly with liquid. For small blisters (with a diameter up to 5 mm) piercing the blisters is usually not useful, since the safe handling of the thick needle is difficult and injuries can easily happen. With a small child or baby you could also damage the surrounding skin while trying to hold them down.

Blisters in the mouth **should not** be pierced.

When washing by bathing or showering does not appear sufficient, some wounds may need to be cleaned again. You may sparingly use an antiseptic (=disinfectant), that you can spray on the wound and then allow it to dry. Then you can use various ointments, wound dressings and swabs to cover the wound. Crusts that have not completely dissolved by soaking can now be carefully removed. You then need to decide if ointments, creams or dressings should be used and if so, which ones are needed.

There are a few things you should know about and that you should pay attention to if you need to care for wounds caused by EB:

- In general, there are no deep, but rather superficial wounds. Deeper wounds are a warning and are a reason for a doctor's visit.
- You will quickly get used to (have to) the fact, that you will always find skin wounds when you have EB, no matter how good or even perfect you take care of the skin. Some heal quickly and easily, others exist longer. Unfortunately in the more severe forms, such "chronic wounds "are often seen as a steady state. If the healing of a wound takes much longer (approx. 2 – 4 times as long) than in a normal case for you or your loved one, then that is also an indication of a problem that should be investigated by a doctor.
- For normal uncomplicated wounds use simple care or ointments.
- For slightly moist wounds we rather recommend drying creams and ointments. For dry wounds and scabs, you can use wet or oily creams or ointments.
- Even the skin without wounds usually needs special care; you can use a cream or lotion that is pleasant to the person concerned.
- Together with your medical and / or nursing caregiver you will quickly find highly suitable products.

- In places that are hard to cover with a dressing, a smooth zinc-containing skin cream should be used to dry out the open blisters.
- With infected, oozing and / or malodorous wounds please be sure to consult a doctor. Usually an accumulation of bacteria will be the cause of this type of wound. Different products are available to reduce the bacteria. We often will use Flammazine cream. This silver-containing cream works well against bacteria. However, it should only be used for a maximum of 2-4 weeks because of silver toxicity with prolonged use. Also antiseptic washes, baths or antibiotic ointments may be necessary.
- For wounds that somehow appear "different" for any reason you should seek medical advice.

Of course you will need support in the beginning. Let us therefore help you with these decisions especially in the beginning; you will very quickly learn to decide what you need for each wound.

5. Changing and Applying Dressings

Please do not forget: with EBS generalized severe cover only the wounds that must be dressed. For small, uncomplicated wounds and sores it often enough to apply an ointment or cream that slightly moistens or dries out the wound as needed.

The order in which one applies the dressings does not really matter, but it is helpful to develop a routine. The following procedure has been proven to work well: Starting with the legs one person works upwards applying the dressing while another person hands over the dressing materials or (with young children) will keep the leg still.

Only materials that are non-adhesive should be used in wound care. Adhesive dressings can cause major skin damage in people with EB as soon as one tries to remove them! And please be careful: Many dressings which are referred to as "non-stick" behaves differently on EB skin. Meanwhile, there are a variety of suitable materials and you should test different ones. Not all material is suitable for everyone and unfortunately not all suitable material is available in every country. There are also different rules from different health insurance companies, and they will not accept the expenses for all materials. We have had the experience that ultimately almost always a useful material is found.

[The following 3-step dressing technique has proven itself:](#)

1. Direct Wound Covering/Dressing:

Directly on the wound either a mesh or a soft foam wound dressing is applied. The open areas of skin are then carefully covered, so other overlying dressings will not stick to the wound and can cause further skin damage.

If a cream or ointment is needed, it may be applied either directly onto the wound or first onto the dressing that will then be applied over the wound. Most patients prefer not to have it applied directly onto the wound.

Bandages which have already proven themselves useful for EB are mesh dressings e.g. Adaptic® (Systagenix), Urgotül®/Urgo® soft (from Urgo), Mepitel® and (Mölnycke).

Furthermore, foam dressings may also be used. The best known for EB patients is probably Mepilex® and (Mölnycke) - soft foam silicone coated-dressings. However, there are a variety of other products that can also be used. Make sure you get advice from knowledgeable people. If possible find a support group in your country which can help you with selecting the materials you need. Fortunately there are now DEBRA groups in many countries of the world and there you will find people who have a lot of experience and know exactly which materials and products are well suited for a person affected with EB.

If for any reason you are not able to provide these materials for yourself or your family, then you somehow have to improvise. We have known families who use cotton towels as a dressing. Sheets or bedding are suitable for this; they can be cut into strips or squares. Together with creams and ointments you can use these cloth pieces for wound dressings. These types of dressings usually loosen easily if you use enough ointment so that nothing sticks. Of course, these towels have to be very clean. They will not be as sterile as modern, individually packaged dressings. However, by washing them in a washing machine at 95 ° and/or hot ironing you can remove bacteria at least for the most part. And as mentioned beforehand: This is for families who do not have access to other materials. If the alternative is that wounds will not be covered, then our view is that this is still acceptable.

But we hope very much that the DEBRA groups around the world can fight for the right for an adequate supply of modern, appropriate dressing materials for all the families affected by EB!

2. Padding:

Soft dressings are applied directly to the wound. This type of dressing serves both as protection and also for absorbing wound exudates. This padding is necessary, especially when using a mesh; yet when using foam pads you can often do without it. You can use products from many manufacturers (e.g. Topper 12 from Systagenix, Medicomp[®] Extra or Medicomp[®] Non-woven swabs from Hartmann, Vliwasoft[®] woven compresses from Lohmann & Rauscher, etc.).

3. Fixation:

In order that the wound dressings and pads do not slip, they must be secured. For this purpose there are bandages manufactured by many companies. Bandages, such e.g. Peha-haft[®] (pay attention that they are not too tight) or elastic tubular bandage e.g. Cover Flex[®] Hartmann are appropriate. Ask which bandage supplies are offered by your health insurance company and try the different gauzes and tubular bandages and use the ones most suitable to you. It should be soft and elastic and it should feel comfortable. Fixation bandages should be soft and pleasant to the person that is wearing them.

Clean up:

Finally, you should immediately dispose of the resulting packaging waste and all the old remnants of dressings so that the germs contained in them cannot be spread. That way you can also avoid unpleasant odors as well. Clear away the remaining material and also clean the dressing station. Ideally, at the end of the dressing procedure, you should wipe down the dressing area completely with a surface disinfectant. There are excellent disposable disinfectant wipes (e.g. Bacryl-of[®] from Schulke). Leave the room in a clean state so that you can return to it at any time to prepare for the next dressing change.