
GENERAL INFORMATION FOR WOUND CARE

1. Introduction

Blisters and sores are part of the lives of all people living with EB - but in highly varying degrees. The proper care for blisters and sores is therefore necessary for all concerned, as it is a part of everyday life that needs to be addressed as best as possible. How to do this depends on several factors. The two most important are the EB-type and the age of the person concerned. In addition to these, there are other factors such as nutritional status, the general condition, the current condition of the skin, the availability of dressing materials, the possibility of home care and the home environment. The need for and the intensity of treatment changes from day to day, and there are many different materials (dressings, ointments, aids) that can be used to adapt the treatment for daily life, work and social circumstances.

Important points in a nutshell

- **The nature and cost of wound care depends on many factors:**
 - **Type of EB**
 - **By age**
 - **The general perception**
 - **From the current skin condition**
 - **From nutritional status**
 - **The home environment**
 - **From the availability of dressing materials**
 - **From the amount of assistance with care**
- **It is important that these factors are taken into account, so that the wound care can be well planned and prepared for.**

2. General Information

Before we deal with the dressing techniques we want to bring you a little closer to these factors, which play an important role for good and practical wound care.

EB-Type

The type of EB you are dealing with makes a big difference in wound care. One can imagine that with a localized form in which blisters and sores "only" occur on individual parts of the body and not continuously, the dressing can be performed much faster than with a more generalized form, in which a much larger proportion of the skin must be cared for with bandages. The general principles of wound care are very similar for all forms of EB, but differ significantly in the extent and the necessary amount of time needed. There is also similarities despite differences in approach that are set by the type of EB, therefore we will discuss in further detail (special section for wound care) the characteristics of the individual EB types.

Age

In newborns and infants, it is important that parents and caregivers are initially well instructed to ensure that the dressing changes may be performed quickly and safely. You should get all the information that is available to you. There are different types of dressing changes that can be done using many different materials. Not all are suitable for every child, so it makes sense to get advice from experienced people. In babies dressing changes can be the easiest if they are removed during a bath. How this can be most comfortably done and what you should pay attention to will be described later. There should always be two people available for dressing changes, so that one person can hold the baby properly while the other person applies the dressing. It is not easy, anyone who has had to change a diaper on a kicking wiggling baby knows how hard it will be to properly apply a dressing in the right place, not too tight and not too loose all alone!

Of course, in the beginning it will not be so easy especially for the parents, but most learn how to do it much faster than they would have believed for themselves. Make sure you ask for explanations for exactly what you want to know. Feel free to ask more questions if you have not understood something or if you have any doubts.

Infant/Child:

At this age dressing changes can be best performed with two people, so the time needed is kept as short as possible. How the dressings are changed depends on the circumstances. Depending on whether the child has a few or many wounds, whether the child is happy while bathing or whether bathing is uncomfortable for them, you will need to decide which method might be the best. Since the time that is needed for the dressing change can be long, despite quick and efficient work of course distraction is permitted. Listening to music or a story can be of assistance. If it is possible you should not always use distracting measures, for the child should actively start to participate in his care at some point. When they are completely involved in a computer game then they will not be able to actively help. This extends the time required, and ultimately means that the child leaves it to others what will be done with them. However, they should learn more and more that they are also responsible for themselves, their body and their skin. Therefore, it is now more important that the child learns to understand what is happening with them and most importantly why. Therefore, as soon as it is possible, the child should help with dressing changes. Then it is not just something that "happened to them", but something that they have at least a little influence on and where they may actively help. This has proven to be very helpful for dealing with the disease later on.

Tasks that the child could take care of for themselves are for example the removal of dressings, the puncturing of blisters (as soon as the motor skills of the child's permit this), applying moisturizer, the application of dressings, etc. However, there is no fixed rules because all children with EB are different, and you will need to judge the very individual skills and abilities of the child concerned.

During the so-called "terrible twos" phase, which children with EB also go through, the dressing changes can be a huge burden on parents and children. Especially during this time it may be helpful if someone can do the dressing change "from outside", for example a home care service. You have to expect at this time that you often have to compromise and "perfect" wound care is not always feasible.

Adolescents and Adults:

With adolescents and adults who suffer from EB, we assume that they already personally assume responsibility for the care of their skin, blisters and sores. A lot has already become daily routine, the person has already learned how to handle his skin. Depending on how severely pronounced EB is in a particular case and what are

the additional problems they may have, the action for responsibility for their own care will vary. Some things you can perform by yourself and sometimes only instructions can be given as to how you want things done, but the execution needs to be performed with help from someone else.

With milder forms of EB, e.g. with localized EB simplex, wound care will be carried out with increasing independence. In other forms some help is still needed, for example for wounds that are difficult to reach, or for care when you need more than two hands. In severe forms of EB, where large wound areas must be treated, or for problems with dexterity, the person concerned will have to adjust to the fact that they will depend on others to help during dressing changes throughout their lives.

General Condition

How wound care can be performed also depends on the general condition of the person concerned and often by the opinion from the care giver. In times of an additional illness, for example influenza, the wound care will have to be reduced to the essentials. Baths for removing dressing are then difficult to perform. Likewise, the general condition during times of stress (through school, work, strife, stressful relationships, ...) on any given day determines whether the person experiences more pain. Whether the stress or pain is caused physically or mentally does not matter - the poor general condition makes wound care difficult and probably affects the healing process.

Current Skin Condition

How you carry out the care for blisters and sores should depend mainly on the current condition of the skin. Individual skin wounds are of course easier and especially faster to care for than care to large wound areas. Not only the size of the wound area has to be treated, but also the condition of the wound itself plays a major role. There usually are fresh blisters and open wounds to care for daily. Fresh blisters often do occur next to oozing wounds, infected wounds, scabs and dry areas. In addition to these there are problems such as poorly healing wounds, infections, sticky dressings, itching, dry ("cracked") skin, pain, odor and other problems that are caused due to intense heat and profuse sweating. The care of the not - or perhaps not - effected skin should not be neglected, especially if it tends to become dry.

Nutritional State

It has long been known that diet plays a major role in wound healing. The better the body is supplied with nutrients, the better the work processes in the body, including wound healing. In a disease such as EB, where it is a permanent condition that wounds repeatedly incur, many more nutrients will be needed than for those with healthy skin. Therefore, nutrition must be given special attention and for this reason we have a dedicated section for EB dietary needs. We would like to mention, that it can be particularly difficult to achieve adequate nutrient intake in forms of EB that have the most blisters and sores which unfortunately complicates the healing process. This has the consequence, that the wound care with these forms of EB has additional requirements if you want to improve wound healing.

In contrast with the forms in which comparatively little wounds occur that heal quickly, it is not so important. But the basic principles of a balanced and healthy diet even with these forms are enough, as a one-sided, generally unhealthy diet, can also cause a lack in nutrients (for example zinc and iron) and lead to difficult wound healing - even in milder forms of EB.

Home Environment

First, you should consider where there is a good place in your home to perform the dressing changes. Of course, which place this can be depends on your personal living conditions. Very few families can provide a separate room, but you'll certainly find a suitable area.

It is initially indifferent to what the form of EB is, even if the space requirement for milder forms of EB is usually smaller. The age of the person concerned, and their size is more crucial for the preparation and in the course of life you will need to adjust the space again and again. We would like to give you a few suggestions, ideas and information on how this can be done.

Please avoid if at all possible the bed of the individual concerned as the location of dressing changes. It should especially be avoided with small children. My own bed should be a "safe place" for all people and especially for children with problems a place of well-being and a retreat. The not unpleasant actions - as is with dressing changes - even with the best technique and routine, should not be brought into connection with their special place.

For most babies, the changing table is also the dressing change table. It is practical when this is in the bathroom (to be folded down as a "folding table" from the wall) but if the bathroom does not have enough space for it, it also can be used in another room.

It is important that the changing table:

- Has a soft padded surface, where you can lay down one or two soft cloth diapers.
- There is protection against the baby falling.
- Is in a nice warm place - cold wounds hurt more!
- Is high enough that the care givers can work without getting back pain.
- Offers enough space that two people can perform the care.
- There is space nearby for the prepared dressing materials.

In infants, the changing table will quickly become too small. You therefore need to create a larger place, which differs only in the required size of a dressing table for children, adolescents and adults.

A narrow, large, sturdy table that is accessible from at least two sides, would be appropriate here. Again, it is important to pay attention to the correct height for the care givers, ideally it would be a height-adjustable table (i.e. massage table). Then a soft pad should be placed, which may be made of foam or similar material, and on which the parties concerned can sit or lie comfortably. If the area does not have to be prepared every day, then a mattress also provides a good surface. Use of one or more blankets is possible. (If the use of a height-adjustable bed is available, this is also a possibility. It should not be the sleeping bed of the individual concerned, as already mentioned before!). A waterproof sheet (in order to avoid contamination of the pad) should be used together with a soft cover, for example a sheet or a towel.

In this case it also important that the dressing table:

- Is equipped with a soft pad.
- Is in a nice warm place (cold wounds hurt more!).
- Is high enough that the carer can work without getting back pain.
- Offers enough space that two people can perform the care
- There is a place nearby with the dressing materials.

We are aware, that it is not always easy to prepare a good dressing station and you often have to improvise. Since EB is a disease that lasts a lifetime, it is at least

worth gradually trying to meet your own needs by creating and adapting a space (this is for patients and caregivers!)

Also, remember that you need to have sufficient space for storage of the dressing materials. The space required depends of course on how much material is actually used. It is not always possible that such a place (usually a cupboard or a big drawer) next to the location of dressing changes is available. Then you will need to find another place and BEFORE any dressing changes remove the material that you will probably need and carry them in a basket or a plastic box to the place where dressing changes are performed. A lot of patients have such a box, which they stock up and then take on day trips or vacation.

You may need (especially for direct wound dressings) to cut some bandages because the specified size does not fit or a special form is required. You should have these items ready before removing the old dressings. This "stocking up" work can also be done while relaxing (e.g. watching television or listening to music) cutting out more than needed at one time, then storing them in a clean box ready to use.

Perhaps you also have the possibility to create a diversion in the area of the dressing station. If dressing changes take longer, a simple CD player can be played with music or an audio book - this has been a well proven diversion.

Dressing Materials (general)

Thankfully, there are now a variety of products that are suitable for wound care for EB. In this area a lot has happened in recent years. However, it is still not easy to find the "right" material for that special person. What is good and suitable for one person, may appear unsuitable for the next. The assessment of the individual products for the person themselves, or in babies and young children, are always done by the parents or caregivers. In specialized centers for EB one will be offered a number of suggestions. These various materials you should use one at a time, and once you have found one that seems right for your needs and one you can work with: keep it. It makes little sense to change the dressing type repeatedly to try new ones. However, if you are in any way dissatisfied or have changed skin integrity or other needs, then you should not hesitate to seek new possibilities together with your care team.

Deciding which wound care materials should be used has been shown by experience and they cannot always be met entirely free from external circumstances. The availability of the products locally as well as the financial aspects must also be considered. There are different products in different countries, not all are available in all places.

The financial means also plays a role. The health insurance companies do not generally cover the cost of all available materials, especially for very similar products - less expensive ones are preferred by the health insurance companies. This is often useful and easy, but can (e.g. for difficult wound conditions) become a problem in some cases and require lengthy discussions with the insurance companies. We are fortunate here in Austria, since we are generally in the position where we receive many materials from the health insurance, even if you sometimes need to pay a premium. In many other countries of Europe and the world it is far from self-evident that the cost of bandages, ointments, creams and medications are covered by the health insurance. If you have to pay for these materials yourself, which are indeed needed with EB in large quantities, the cost factor is of course much more of a burden. Unfortunately, in these cases compromises often have to be made, as the most suitable material is not always affordable.

Assistance in the Care/Home Care

The times in which the dressings must be changed are felt by many families as the most difficult and stressful ones. The more severe the skin is affected, the longer the time is needed for a dressing change. To make this time as bearable as possible for all parties involved it is not only good dressing technique that is needed, there are also other important aspects. For a smooth process, it is desirable that at least two people are available to perform the dressing change. Especially in infants and young children it is hardly different and only with great effort feasible to do it alone. If at all possible, families should receive support from a home health nurse.

From the beginning, parents should always pay attention that not only one person is taking care of the dressings. As a parent (in our culture still mostly the father) has to work so soon after giving birth, the main burden of care rests with the remaining parent at home, usually the mother. Nevertheless, both parents, other relatives or friends should (and can!) - in any case - also learn how to take care of the dressing. In addition or as a supplement a home health nurse should be used. This is in many instances the only way to prevent in the future, that the mother of the child is the

only one that the child accepts as carer. We are aware that this is not always so simple, but it's worth to try. The mother needs her time off and if she wants to be there entirely for her child, then she must also have the opportunity to recover at least temporarily and get free time. Then with sudden absence of the mother (e.g. through her own illness), there is always someone available who is familiar with the care of the child.

Every family and every one of the EB sufferers will find a way, on how the dressing change can be done in a safe and quick manner. Find out from our suggestions which of those appear feasible and useful for you. Dare to try new things, make mistakes, learn from them, try something else - until you have found the right way. Do not be shy in front of your doctors, nurses and other affected families to ask for advice when problems appear. Then you will ultimately work out a good solution on how to make the time for wound care efficient - and then still have time and energy left for many other areas of life.