

CLOTHING AND EBS, KINDLER SYNDROM

1. Introduction

Clothing plays an important role in the lives of those affected by EB as much as people with normal skin. You can contribute much to your personal wellbeing when the clothing is comfortable and conforms to your personal taste.

On the other hand, special demands on the material are required in EB. Due to the resulting friction, there can also be problems from rough seams, fasteners, etc.



Important points in a nutshell

- **Soft and breathable materials are more suitable.**
- **Avoid rough labels, tight elastic, and seams.**
- **If necessary use UV-protective clothing in summer.**
- **Special Materials such as Dermasilk® may be helpful.**
- **Ensure that your footwear is soft and breathable.**

2. Tips for suitable clothing

- The materials should be soft and comfortable.
- Breathable materials are preferred. Particularly suitable are cotton, silk, viscose, bamboo fiber, and the new materials from the sport industry. The experience with the use of underwear from special skin friendly materials (e.g. Dermasilk®) has been good.
- Remove all labels and avoid rough seams, narrow cuffs and waistbands.
- Make sure that your clothes are easy to put on and take off and have wide necklines.
- Avoid Buttons, zippers, buckles and seams that can cause pressure points.
- Do not dress too warm because the blister formation is enhanced by sweating.
- Blended fabric with stretch while not breathable is soft and cuddly!
- It has been proven useful for some babies, that turning the garments inside out reduces friction from the seams. Likewise, underwear can be turned inside out even with larger children and adults.
- Both disposable and cloth diapers are suitable for babies. Some parents find that cloth diapers cause fewer blisters; others have had good experiences with very absorbent disposable diapers. If the cuffs of the disposable diaper lead to increased formation of blisters on the thigh, you can, remove the cuff with a pair of scissors or you can protect the affected area with bandages.
- Prophylactic bandages can protect against rough seams and buttons.
- Onesies (rompers) and overalls have no narrow waistbands; knitted waistbands cause less friction.

- Socks made from soft, elastic material, without elastic cuffs are preferable.
- Pay particularly good attention with regard to the percentage of cotton or natural fiber in your socks when you are prone to sweating feet.
- Depending on age and preference of clothing it should of course be pretty and look "cool"!

3. Shoes

General Information:

Using the same principle as with clothing you should use shoes made of soft, breathable material. The sole of the shoe should be soft and non-slip. If bandages are worn on the feet, the shoe should be correspondingly larger. It is also possible to use bandages to cushion the feet to prevent blisters. You can also use gel inserts or special foams that are also used as wound dressings, for inserts in the shoes to reduce pressure points.

When buying shoes for children it is important to note that they cannot feel for sure if the shoes fit. In children, the nervous system is not yet mature enough, to exactly perceive pressure points. Therefore, children often wear shoes the wrong way without it bothering them. In principle, the shoes should be 12 mm longer than the foot (possibly with bandages) to leave enough room for the rolling motion during movement. New shoes can be 17 mm longer than the foot (possible with bandages) in order to leave room for growth.

Children's feet grow quickly, and should be controlled at regular intervals to check that the currently worn shoes still fit:

for a child from 1 to 3 years every 2 months,

for a child from 3 to 4 years every 4 months,

for a child from 4 to 6 years every 6 months.

If you try "check the toes " by feeling from the outside when trying on the shoes, where the big toe of the child is, the child often pulls the toes back.

Alternatively, it is advisable to place your child's foot on a piece of stiff cardboard (if possible with the usual bandages) and trace around it and make an outline of the foot with a pen. By the longest toe add still 12 mm (17 mm for a new shoe), you can cut out this resulting template and place it in a shoe to see if it will fit.

With many shoes you can easily remove the insole, and then the child can stand on the insole and verify that it is the appropriate size (and width).

There are stores that provide services to measure your feet, and there are also measuring devices for the home you can purchase.

It should be noted that the manufacturers specified shoe size often does not coincide with the actual shoe size; the shoe size is very often smaller than specified!

For more details on children's shoes and feet, see www.kinderfuesse.com (also in German).

Shoes for those affected with EBS and Kindler Syndrome:

It is not always easy to find a pair of shoes which are best suited for you. There are many different opinions of what is best. In any case, it seems to be important that the shoes are made of a soft material and that they are neither too small nor too big and they are well ventilated.

It is also important that the shoes can be opened wide enough when putting them on and taking them off and that no seams exist that can potentially rub. Shoes made of natural materials such as leather or cotton are usually better than synthetic materials.

Gel or sheepskin insoles can help to avoid pressure points on the soles of the feet. Likewise, the feet can be protected with prophylactic bandages and foam dressings, but then the shoes have to have a broader width.

For some a soft, sheepskin-lined boots and shoes are ideal. Others find - if dressings are worn on the feet - that Crocs are (original or replica) very comfortable.

Some families report that shoes that have been worn by a sibling are well suited. There is nothing wrong with using a sibling's old shoes yet keep these two things in mind: size and width must be appropriate and also the sole must be evenly worn down and not worn down on the sides.

Since wounds on the feet even with the same forms of EB can be very differently distributed, you ultimately need to find the right solution for each person, individually. This also depends on the weather and climate.