

CLOTHING AND JEB generalized intermediate, other (rare) forms of JEB

(Not for JEB generalized severe --> own pdf)

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.**
- **Small aids can enhance the independence when dressing and undressing.**
- **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 as sweating can promote the formation of blisters. 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. Please ask your attending physician if this can be prescribed.
- Remove all labels and avoid rough seams, narrow cuffs and waistbands.
- 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.
- Make sure that your clothes are easy to put on and take off and have wide necklines.
- Buttons, zippers, buckles and seams can cause friction wounds. Therefore, they should be either completely avoided or carefully considered when problems occur.
- Do not dress too warm because the blister formation is enhanced by sweating.
- Blended fabric with stretch while not breathable is soft and cuddly!
- But be careful: too much spandex can lead to the clothing sticking to the skin!

- 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. Facilitation of dressing and undressing

To be able to dress and undress yourself is an important step in the development of independence for each child. Since people with JEB can often have difficulty grasping and holding, there is a risk that the daily challenges of getting dressed, take longer than necessary for the child. With a few tricks or adaptations of the clothing, taking garments on and off can be made easier.

- Attach Velcro closures instead of zippers or buttons.
- Fasteners that are flush can be extended with a loop.
- You can sew loops on the sides of pants and underwear to help make pulling them up easier.
- Use clothing with elastic waist bands and cuffs instead of buttons.
- Zippers can be fitted with rings or fabric loops.
- You can attach loops to the lower part of the garment to get a better hold when closing a zipper.
- For independent dressing and undressing leave the zipper part way closed.
- Use large buttons.

4. 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.

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! Therefore, the trying on of the shoe is inevitable.

Because the width of every child's feet is different, the width of the shoe also needs to be considered. This especially needs to be observed when dressings are worn on the feet. Some children's shoe manufacturers specify the width of the shoes (wide-medium-narrow).

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

Shoes for those affected with JEB generalized intermediate and other (rare) forms of JEB:

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 that can potentially rub exist. 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 soft, sheepskin-lined boots and shoes are ideal. Others find if dressings are worn on the feet then 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.