

“We can influence the pain!”

Tips for parents and carers in dealing with pain when changing bandages of children with Epidermolysis bullosa (EB)

Children with EB need to have their dressings changed on a daily basis, which can be extremely painful. Sometimes the pain is more intense when a child concentrates on the anxiety and pain. The same applies to other negative emotions, such as anger, worry, frustration, stress and hopelessness. **Negative emotions and thoughts exacerbate the pain!** They furthermore may cause resistance and difficulties during the dressing change.

PAIN CAN BE POSITIVELY INFLUENCED!

The pain experience can be reduced by positive factors!

Positive feelings

Trust, security

Positive thoughts

„I can do this!“

Positive behaviour

„I distract myself and assist!“

Positive situation

*Everything is well prepared;
the atmosphere is relaxed*

The following factors might also be helpful:

1. Being well prepared:



- Let the child know about the upcoming dressing change at an appropriate time (the child needs time to overcome the first fear reaction).
- Stick to the agreed upon time for changing the dressings. Any delays might intensify the anxiety.
- Prepare the materials in advance and warm up the room and the balms/ointments.
- Create a comforting, preferably relaxed atmosphere.

2. Distraction, distraction, distraction:



- Steer the child's attention to interesting and pleasant things.
- Jointly think about and plan possibilities for distraction.
- Collect the distraction strategies, e.g. on notecards.
- With younger children, include an additional person who can assist with distraction.

3. Emotional support:



- Help the child to overcome the fear of pain through bodily contact, trust, control, humour, bolstering and encouraging language.
- Use a „hero helper“ in order to encourage the child, e.g. the child's favourite movie or book character, who, according to the child, would be able to master the situation.

4. Assisting and having a say/making joint decisions:



- Actively involve the child in deciding when and how the dressing changes will be carried out.
- Let the child assist and take control during the dressing change, e.g. by removing the bandages and pricking the blisters himself/herself.
- Jointly plan distraction strategies, coping strategies and activities to be done after the dressing change.

5. Positive conclusion:



- Emphasize what went well during the dressing change.
- Reward the child with fun activities involving both child and parent.
- Plan some downtime following the dressing changes (stress reduction in parents positively influences the stress management of all involved).

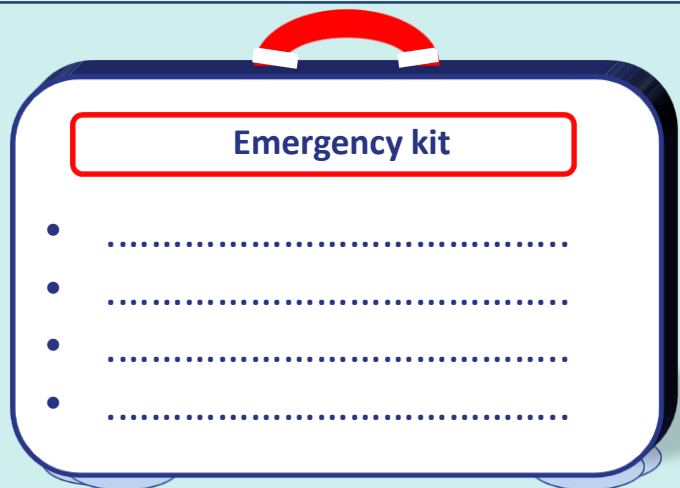
This suits us / this works well for us:

Preparation (Room, materials, relaxation, distraction, assistants, time point, assistance of the child...)	
Distraction strategies (Seeing, hearing, brainteaser, conversation, stories, games ...)	
Emotional support (Encouragement, favourite book / favourite movie character as a „hero helper“ ...)	
Assisting and making joint decisions (What can the child do autonomously? Jointly collect ideas for distraction and conclusion of the dressing change ...)	
Positive conclusion (What can we do after the dressing change that is fun? Is there a specific way to end the dressing change positively? Can a ritual be developed?)	

„Our emergency kit“

→ **This is our plan:**

If the anxiety or stress increases and suddenly everything gets out of control, we will ... :



What else is important?

Collection of ideas

concerning managing pain during dressing changes of children with Epidermolysis bullosa (EB):

Breathing techniques for relaxation (to allow for a feeling of control over the body; tension /stress decrease):

- Taking deep breaths; synchronized breathing with the parent; breathing out slowly (sighing)
- Blowing bubbles or blowing up a balloon
- Clear self-directions: *“breathe in and out; count 30 breaths”*
- **With training:** simplified Progressive Muscle Relaxation (PMR); autogenic training

Opportunities for distraction:

- Concentrate on environmental stimuli (seeing, hearing), e.g.:
 - „I spy, with my little eye...”
 - Identifying all objects that are “blue”
 - How many different sounds can you hear?
- Conversations and thoughts about pleasant experiences or fantasies, that are incompatible with the fear:
 - Pleasant/funny/silly mental images or thoughts
 - Pleasant experiences, vacation memories or anticipations, hobbies, sports
 - Imagine your favourite TV-series. What is currently happening? Which character do you want to play?
 - Jointly imagine a dream vacation/fantasy story
- Brain-teaser, e.g.:
 - Distraction-ABC (find names, profession, cities, etc. for each letter in the alphabet, starting at A)
 - Think of words that can be read forwards and backwards, words that rhyme, or foods that start with A, M and S
 - Write down all birthdates of your friends that you can remember off the top of your head; calculate how old all of your friends are together
 - Dream up a story about a “happy place” (describe exactly how it looks and what you can hear)
 - Dream up a story that includes e.g. the following words: tortellini, frog, sun, balloon...
 - Think of a compliment for one of your friends/family member, write it down and give it to them later
 - Compose a poem
- Humour, clowning about, fooling around, singing
- Looking at comics, reading books, searching for specific items in hidden object books
- Telling fairytales and stories; reading to somebody; playing with hand puppets
- Listening to an audio book or music; watching a movie or funny Youtube-videos; playing with the Game Boy or tablet; playing electronic education games
- Game suggestions: puzzles, Origami animals, drawing exercises (e.g. drawing 5 animals with more than 4 legs)
- In the bathtub/shower: e.g. water games, sailing paper ships, making soap bubbles

Influencing own thoughts/Self-control/Encouragement:

- Turning the “negative” into “happy” thoughts, e.g.:
„If I distract myself, I can stand the pain better”, “There are many things that I am looking forward to”, “Other people have problems too”, “I will think about the things that have helped me before”, “I can help myself”
- Stopping negative thoughts from occurring: think of a stop sign or a gate: *“Stop! Quit thinking about it!”* and instead think about pleasant things: *“What will we do after the dressing change that is fun?”*
- Emergency kit: jointly come up with specific strategies for emergencies, e.g.:
„If I suddenly get scared, I will deeply breathe in and out and will travel to a happy place in my imagination.”
- Positive self-instructions: Guidance by parents / carers:
 - *„I can do this!”* • *„We can do this together, I will support you.”*
 - *„I can assist myself!”* • *„It won’t take much longer.”*
 - *„I can stand it!”* • *„We will do exactly what we practiced before.”*
- Hero helper: Include the child’s hero, e.g. a favourite book/movie character, who would master the situation: What would the hero do right now? E.g. *“I can roar as loudly as a tiger!”*

Possibilities of stress reduction for parents:

- Self-control techniques: Positive thoughts, stopping unpleasant thoughts, „emergency kit”
- Relaxation techniques (breathing techniques, autogenic training, PMR, Yoga)
- Relieving conversations
- „Teamwork” – shared responsibilities
- Have a plan to balance the stress, create an „island” where you can retreat. Your needs are important too.
- Courage to do it your way: there is no one correct way of doing things!



Kinderpalliativzentrum
Vestische Kinder- und Jugendklinik Datteln
Universität Witten/Herdecke

Further information can be found:

- in the booklet ***„We can influence the pain“***
www.kinderpalliativzentrum.de
- and in the video ***„Living with Epidermolysis bullosa – coping with pain during bandage changes“***
www.youtube.com/watch?v=HV_V4jl6zK8