



Paediatric Palliative Care Centre
Children's and Adolescents' Hospital, Datteln
Witten/Herdecke University

“We can influence the pain!”

Tips on dealing with pain during dressing changes

Information brochure for parents and carers of
children with Epidermolysis bullosa (EB)



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DATTELN, GERMANY, JULY 2018

KINDLY SUPPORTED BY DR. AUSBÜTTEL & CO GMBH (DRACO)



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Dear Parents,

Due to the skin condition Epidermolysis bullosa (EB), your child is in need of frequent dressing changes that potentially are very painful. Besides the pain, dressing changes may frequently elicit anxiety and stress in your child. Perhaps they have the same effect on you. You might have noticed that your child's pain perception varies highly in intensity. Sometimes they perceive relatively little pain, other times the pain is so intense that dressing changes are hardly bearable.

"Life with EB is like a 24 hour rollercoaster ride, 365 days a year."

This quote from a mother exemplifies that the daily routine and the dressing changes themselves are different every day. Perhaps you also experience days in which the dressing changes are extremely difficult and painful, and other days in which the entire procedure somehow is conducted more easily.

In this brochure, we would like to explain which factors potentially influence pain and point out possible ways you and your child can influence the pain positively during dressing changes. Your child can learn to actively cope with the pain. They can then take an active role during the dressing changes. Hence, instead of feeling helpless they can feel self-sufficient and in control. You can support your child in this!

We will furthermore illustrate how you can manage your own stress during the dressing changes and where you can find help. Once you understand the influencing factors of pain and know about strategies for pain management, you can support your child to actively cope with the pain. The dressing changes can thus be performed more easily, and hence chronic pain disorders can be prevented.

You are the expert when it comes to your child. Thus, you can judge best what works well for you and your child. *We* are the experts for dealing with pain in children – our suggestions and tips included in this brochure are based on years of experience of therapists, doctors, and carers who work with families in the Paediatric Palliative Care Centre and the German Paediatric Pain Centre in Datteln, Germany.

You can find further information about us at the end of this brochure.

Dear Carers,

When caring for children with Epidermolysis bullosa (EB) you very likely experience highly variable situations when dealing with different children and families, but also when dealing with just one child. Sometimes the dressing changes can be conducted relatively easily, sometimes they are very difficult for everybody involved.

Do you ever wonder where this fluctuation comes from? In this brochure, we would like to illustrate influencing factors on pain and helpful strategies for influencing pain, thus changing the entire dressing process. When it comes to dealing with pain, we have been able to gather years of experience and a lot of expertise by working at the Paediatric Palliative Care Centre and the German Paediatric Pain Centre at the Children's and Adolescent's Hospital Datteln – Witten/Herdecke University. We would like to share our knowledge with you!

You are in very close contact to the children and families. Thus, you can pass suggestions and tips on to them and apply them yourself. Details about where further information can be found are listed at the end of the brochure.

Several carers for children with EB mentioned that an additional brochure exclusively for carers is not required, but that the brochure composed for parents will

suffice. Thus, we will directly address the parents in this brochure and indirectly address you as carers. Please also regard our ideas and suggestions as stimulation on how to instruct the children and families. You as a carer can instruct parents once you know about influencing factors on pain and pain management strategies and thereby help children to actively cope with pain. The dressing changes can thereby be eased and chronic pain disorders can be prevented.

There is no one right way. Strategies that are helpful today may not be helpful tomorrow. Be encouraged to creatively try out proven and new strategies, and always be open for the families' individual ideas.

Pain – doesn't everybody know what it is?

Something worth knowing:

In order to better understand how to positively influence the pain during dressing changes, it is useful to have more knowledge about pain in general. Pain can be very distinct. Hence, everybody experiences pain differently.

Which kind of pain do children with EB experience?

Children with EB mostly suffer acute pain, which first and foremost constitutes a warning and protective function for the body. This pain is elicited by the disease itself (e.g. blisters, wounds, indigestion ...), or its treatment (dressing changes, medical measures, physiotherapy ...). Additionally, children with EB suffer the types of pain that everyone experiences in their lives (toothache, headache, stomachache ...).

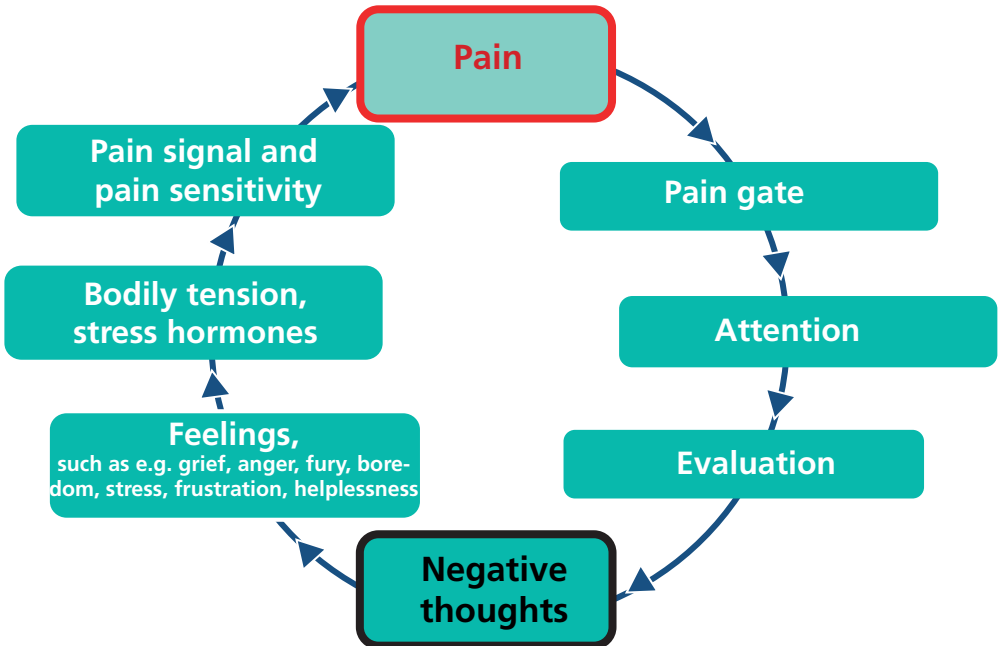
Due to the frequent and recurring pain experiences, children with EB are at risk for developing a chronic pain disorder. Chronic pain is independent of external stimuli and does not serve a warning or protective function, but constitutes a disorder in itself. The **vicious cycle of pain** explains how chronic pain develops and is maintained:

What is the vicious cycle of pain?

The "feeling" of pain arises in the brain. A pain signal is sent to the pain centre in the brain through the spinal cord. Depending on how much **attention** this pain signal is given, the pain is perceived as more or less strong. To understand how this works, you can imagine a "**pain gate**": if the gate opens widely (= much

attention to the pain), a lot of pain arrives in the pain centre, and the pain is experienced very intensely; if the gate is barely opened, e.g. due to distraction, (= little attention to the pain), the pain stimulus is experienced as being weaker. Before the pain "arrives" in the pain centre, it is already being **evaluated** (mostly negatively, e.g. "Oh no, not again"): these **negative thoughts** intensify the pain, while positive thoughts (e.g. "I can handle this") attenuate the pain. Besides the evaluation of the pain through thoughts, **feelings** also play a big part: You can probably already anticipate it: Negative feelings such as fear, anger, and helplessness have the power to intensify the pain, while positive feelings such as courage, trust or feeling supported instead of pitied, can attenuate the pain. The power of feelings is tremendous: negative feelings cause the body to **tense up** and thus elicit the release of **stress hormones**. These processes in turn intensify the **sensitivity to pain** and the **pain signal** – meaning that one becomes even more susceptible to the pain, sometimes even on the surrounding "healthy" skin. The brain "learns" the pain and creates pain memories.

Vicious cycle of pain



You can support your child in breaking the cycle or, to prevent it altogether.

Which factors influence the perception of pain?

Why does it sometimes hurt more and sometimes less?

The pain experienced during dressing changes can be influenced by three main factors: that is your child, yourself, and the situation in which the dressing change is conducted.

For *children*, the expectation of an unpleasant experience plays an important role, and fear is the strongest feeling in this situation. The fear of the dressing change can be linked to the pain itself, which makes the two feelings indistinguishable – for the child as well as the carer. Additionally, the experiences are a crucial factor: if children recurrently experience or fear uncomfortable situations (-> negative thoughts), it can strengthen their anxiety and helplessness (->negative feelings) and lead to disadvantageous behaviour, such as tensing up or refusal to cooperate. The younger the children, the more difficult it is for them to understand their thoughts and feelings and to control their behaviour.

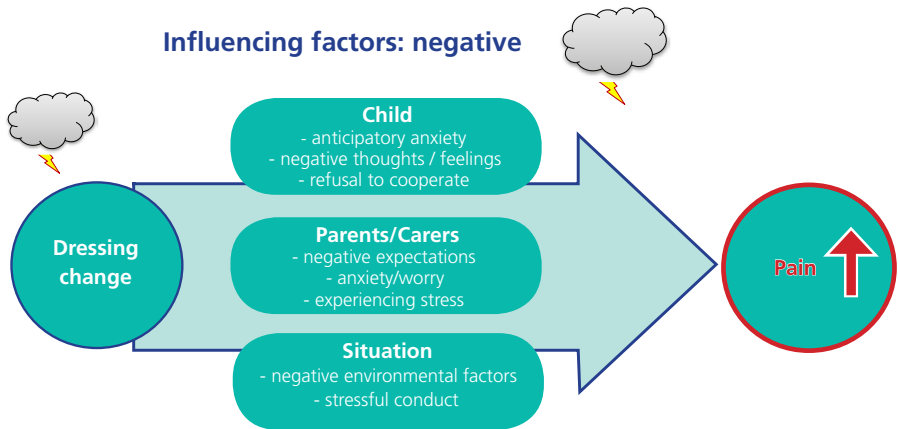
As described in the vicious cycle of pain, negative thoughts, feelings, and behaviours intensify the pain.

Every *parent* wants to protect their child from painful experiences – children with EB often experience pain on a daily basis. Not being able to protect the child from such experiences is often difficult for parents and elicits stress, worry, and fear/anxiety; parents mostly react by comforting their child. By doing so, they hope to enable their child to better cope with the situation, to feel cared for and to forget the pain as soon as possible. Exceedingly few parents know, however, that they

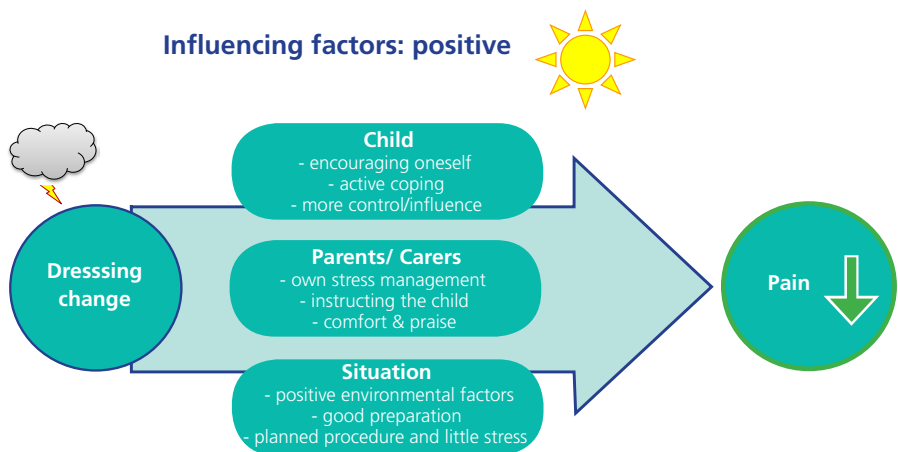
can exacerbate their child's pain and thus their level of stress through their own behaviour. If, for example, they anticipate their child to experience intense pain (-> negative thoughts) and experience anxiety in anticipation of the dressing changes themselves (-> negative feelings), they will inevitably show their concern through facial expressions or worried comments. This is a warning signal for children: there actually is a reason to worry!

Thus the parent's thoughts, feelings, and behaviours potentially influence the child's pain perception as well!

The *situation* in which a dressing change is conducted plays a crucial role in how the child experiences the pain by influencing how much attention is directed toward the pain. What you as parents cannot influence are factors such as the current skin status, experiences of stigmatization, or exclusion in school and the neighbourhood. However, you can focus on the following aspects that influence your child's mood: unpleasant environmental factors such as coldness, noisiness, or the sight of many medical utensils. The timing is also crucial: delaying or taking the child by surprise with the dressing change, lacking information and agreement, interruptions, or unprepared materials can cause difficulties during the dressing changes.



As all these negative factors can influence the pain, so can positive factors! You can use this for your advantage! We can turn the tables.



If you know the influencing factors of pain, you can positively influence the pain experience.

What your child can do

- and how you can instruct and support your child

There are several possibilities of reducing anxiety and pain: relaxation exercises, distraction, positive thoughts, and much (self-)control. We will now introduce each of them.

Relaxation

Why relaxation is very important for your child, and how it can be achieved

Relaxation techniques help children to acquire control over their own bodies. They thereby experience that they have influence on their bodies. Stress and tension are reduced -> the body relaxes, and the sensitivity for pain diminishes (see the vicious cycle of pain). Relaxation exercises in preparation of the dressing change (e.g. breathing techniques) may help to prevent tension and anxiety from building up in the first place. It is

important to let the child know of the designated time point for the dressing change well in advance in order for them to have some time to overcome the first stress reaction and tension. Relaxation techniques during the dressing change may also be helpful in alleviating tension. Besides breathing techniques, loud emotional expressions can be beneficial. Children intuitively try to conquer the feeling of anxiety and helplessness by, for example, "screaming out" the pain ("roaring like a lion"). Hence, this is a "healthy" reaction by which negative feelings are made bearable. After the exhausting dressing change, the experienced stress gradually decreases. To support this relaxation, breaks and distraction, pleasant activities, and praise are beneficial. Established rituals can also help to alleviate the tension and to conclude the dressing changes positively.



Simple breathing exercises facilitating relaxation

- Taking deep breaths (clear instructions: “calmly breathe in and out; slowly count 30 breaths”...)
- synchronized breathing with the parents
- slowly and loudly exhale
- blow bubbles, or blow up a balloon

Relaxation exercises requiring some training

- Progressive muscle relaxation (PMR): the muscles in distinct body parts are contracted one at a time, kept contracted for a certain amount of time, and then are relaxed again. It is important to actively pay attention to the pleasant feeling of relaxation.
- Autogenic training: in the course of a “journey through the body”, the child imagines how all body parts sequentially become warm and heavy and thereby relax.

Further tips on how to reduce tension:

- Focused loud emotional expressions such as roaring like a lion: screaming loudly is one possibility of how to cope with and bear difficult situations. You can even encourage your child to do so: “Great! You can roar as loudly as a lion!”
- Humour, laughing and movement

What your child can do

Distraction

Why distraction is crucial, and which ideas may be helpful.

Distraction is the key for keeping the pain gate closed and thus to prevent the majority of pain signals to pass it - hence, to redirect the attention away from the pain! Jointly think about and plan distraction strategies beforehand. You can write down the distraction strategies on little note cards and collect them in a "distraction box". Prior to each dressing change, your child can pick a distraction strategy suitable on that day. You should have all

items needed for the respective strategies handy. For younger children, you may want to include a second person to be in direct contact with the child in order to redirect the child's attention away from the pain toward the distracting game or toys.



There are many distraction strategies that you have probably employed yourself for a long time; maybe you can find new inspirations in our collection of ideas:

**Concentration on environmental stimuli (seeing, hearing),
e.g.:**

- Look for everything that is (e.g.) “blue”.
- How many (e.g.) “red” things can you see?
- How many different sounds can you hear?
- “I spy with my little eye...”

Digital media, books:

- Tablet, digital education games, funny YouTube-Videos
- Watching movies, playing Gameboy
- Listening to music or audio books
- Reading books or comics; looking at hidden object books

**(Together): Focusing on imaginations/fantasies that do not
go with the pain (pleasant, funny, silly):**

- Humour, making jokes, fooling, singing
- Telling or reading out stories
- Playing with hand puppets
- Talking about positive experiences, hobbies, sports; talking about positive/pleasant memories of vacations; funny or silly thoughts
- Making use of imagination: *“Think of your favourite TV-series. Which hero would you like to be, and what adventures will you have?”*; or go on a dream journey/visit a safe place together

What your child can do

Ideas for games that (temporarily) are suitable during dressing changes:

- Puzzles, origami animals, painting, drawing (e.g. *"Draw five animals that have four legs, then draw five animals that have more than four legs"*)
- In the tub: floating self-made paper boats, blowing bubbles, playing water games

Brain teaser for school-aged children:

- Distraction-ABC: *"Starting at A, think about words (e.g. Cities, professions, animals) that start with the respective letter"*
- *"Think of words that can be read forwards or backwards"*
- *"Think of words that rhyme"*
- *"Add up the ages of all family members"*
- *"How do your friends' and family members' names sound backwards?"*
- *"Imagine a story that contains (e.g.) the words: sun, frog, balloon, spaghetti"*
- *"Think of a compliment for your friends and family members"*

Positive thoughts

How negative thoughts can be changed/influenced, and what “encouragers” are.

As negative thoughts intensify the pain and anxiety children experience, it is useful to start the dressing changes with as many positive thoughts as possible. But what can be done if the negative thoughts have already appeared? It is helpful to understand what positive and negative thoughts are, and thus to become aware of them. Negative thoughts, such as: “It won’t ever get better”, are often referred to as “black” thoughts; they work like bad wizardry: they intensify the pain and anxiety, cause tension, and cause you to feel bad and frustrated. They drag you down as if they

were leaden weights hanging on you. Positive thoughts, such as “I can deal with it”, however, are also referred to as “colourful” thoughts; they attenuate the tension, anxiety, and stress and increase the body’s endorphin levels – endorphins are the so-called “feel-good hormones”. Colourful, happy thoughts help you to deal with tough situations. Thus, they work like magic! You can imagine the positive thoughts like a shield or like balloons that lift you up (be creative in conveying mental images). Encourage your child (if they are old enough) to detect their “black” thoughts and to replace them with “colourful” thoughts. It works best if you try to do it with your own thoughts and your own words. These are some examples:

Replacing “black” thoughts with “colourful” thoughts	
<i>“Nobody can help me.”</i>	<i>“It’s best if I help myself.”</i>
<i>“I do not have any energy left.”</i>	<i>“There are many sources of energy I can rely on. I will think about the things that have helped me before.”</i>
<i>“I already know that it’s going to be horrible.”</i>	<i>“If I distract myself, I can stand the pain better.”</i>
<i>“My black thoughts”</i> ...	<i>„My colourful/happy thoughts”</i> ...

What your child can do



If the negative thoughts persist, the **“stop sign method”** might help: Imagine a stop sign, a gate, or a wall – negative thoughts are stopped by these: *“Stop! Don’t think about it any longer!”*. In order to eventually eradicate the negative thoughts, they also need to change their direction (In their imagination, the child turns e.g. left or right): *“Think colourful: What will we do after the dressing change that is fun?”*)

Clear **instructions of an encouraging** nature support the child in standing up to their negative emotions, and thus in turning at the stop sign, so to say. Some

children are able to encourage themselves (self-instruction), others need to be directly addressed and instructed. Here are some instruction examples:

Self-instruction:

- *“I can do it!”*
- *“I can stand it!”*
- *“It won’t take much longer.”*
- *“I can help myself.”*
- ...

Instructions and support through parents/carers:

- *“We can do this together, I’ll support you.”*
- *“You are as strong as ...”*
- *“We will do exactly what we practiced before.”*
- ...

“Encouragers”



There are a variety of possible encouragers that are not limited to encouraging instructions. Additionally, favourite stuffed animals or book/movie characters may help. Children believe in their “hero” to be able to handle difficult and painful situations. What would the child’s hero do in this situation? E.g. *“My tiger would roar as loudly as possible! – I can do that too!”*



What your child can do

Control

Why control is such an important factor, and how the child can take on more responsibility.

Control is the most helpful strategy when it comes to helplessness. Being able to take part in decision making when it comes to situations and procedures concerning (not only) the dressing changes boosts the child's self-esteem and autonomy. It thereby redirects attention away from the pain.

Role plays are a suited way to practice control: They can try out assisting in the dressing change and practice their strategies of dealing with negative feelings. Role reversals foster the ability to put oneself in someone else's shoes: How would the child act as the "carer" and vice versa: How would you act if you experienced a dressing change as the patient? If you plan to change the regular routine of a dressing change, you can practice this new procedure with your child (e.g. the child can conduct a dressing change on a stuffed animal or yourself).

It is recommended to use genuine dressings when practicing.

Wanting to avoid or postpone each dressing change causes the anxiety to increase. The child will know that the dressing change is inevitably coming up – the entire day might thus be occupied by anxiety about it. Hence, it is best to jointly decide on and stick to an appropriate time during the day. Allow your child to **take part in the decision process** whenever they are able to or want to help: children can start to assist during dressing changes even as toddlers. It is furthermore important to **actively** plan possibilities of distraction and coping strategies for emergencies – this enhances the feeling of control for the child, contrary to feeling passively cared for and distracted. The more the child assists during the dressing change, the more they will feel in control and thus will be able to reduce the experienced anxiety.



The following overview illustrates possibilities for the child to be in control:

Practicing/role-playing:

- Removing or applying dressings
- Practicing the (new) order in which the dressing changes are conducted
- Playfully trying out how to deal with difficult situations
- Role-reversals

Joint planning of the dressing change procedure:

- Which distraction strategies are suitable today?
- How can the child calm himself? E.g. utilizing encouragement or the "stop sign method"
- "Emergency kit": planning coping strategies for emergencies (when suddenly everything is terrible): e.g. *"When I suddenly get scared, I will deeply and calmly breathe in and out, and in my imagination I will travel to a place where I feel safe" or "if it takes really long, I will distract myself by playing the ABC-game."*

Beginning the dressing change on time:

- Do not delay the procedure, or the anxiety will take control.
- Stick to jointly agreed upon point in time

Assistance during the dressing change:

- Preparation of materials
- Removing the dressings from certain body parts
- Pricking individual blisters
- Cleaning individual wounds
- Applying ointments
- Handing, holding, or applying dressing materials
- ...



What you can do

- so your child will experience less pain during dressing changes

Do you recall the influencing factors of pain: Besides the child and the environmental factors, parents or other people conducting the dressing change are important determinants of the child's pain experience. Thus, by being well prepared, they can help the child: You might want to ask yourself e.g.: *"How can I best guide and support my child today?"*, or *"Which emotions do I feel when starting the dressing change? Am I full of worry, am I stressed? What is my facial expression like?"*. In the following, we will present possibilities for you to help your child.

Emotional Support

How you can emotionally support and guide your child

The younger the child, the more support and guidance/instruction he or she needs from parents or carers in order to actively be able to cope with the dressing change and thus to attenuate the pain. Through emotional support you strengthen your child, build trust, and convey that you are present to help and provide ideas on how to deal with the situation. You intuitively will do many things right already. Hence, you will probably already be familiar with many of our listed strategies:



Bodily contact:

- Holding hands, hugging (is also helpful for teenagers)
- Holding infants/toddlers
- Holding your child's face in your hands and keeping eye contact, thereby helping your child to focus on you.

Providing instructions / "Coaching":

- *"We will do this exactly as we practiced before."*
- *"Come on, we'll play the distraction-ABC just as we planned."*
- *"Ok, now it's your turn: take off the dressings on your foot!"*

Verbally calming your child:

- Encouraging your child: "Calm down, I am here with you", or "We can do this together."
- Always directly address the child.
- Apologies, pity, or excuses are not helpful.

Calming your child with the help of "helpers":

- Stuffed animal, doll, or favourite (TV/movie) character
- A "hero" from a book or a movie can be a "helper", who the child believes in to master the dressing change well; the helper can support the child in its imagination.
- A new "helper" can be constructed in the child's imagination. This not only comforts the child, but also distracts.
- In advance of the dressing change, a humorous "helper" can release tension and promote distraction.

What you can do

Rewards

- Praise for successful coping (also helpful for teenagers), e.g.: *"You're doing great!"*, or *"Wow, very well done, I'm proud of you!"*
- Emphasize what went well during the dressing change.
- Engage in fun activities as a reward after the dressing change. Plan this activity beforehand.
- Especially for infants and toddlers, a ritual enabling guidance is helpful (*"Now that the bad part is over, we'll do something fun"*).
- Rewards in form of presents can be helpful for kindergarten-aged children if new strategies were tried. The child can e.g. collect points or stickers (discuss beforehand how stickers can be earned, and how many stickers are needed for a certain present or activity).



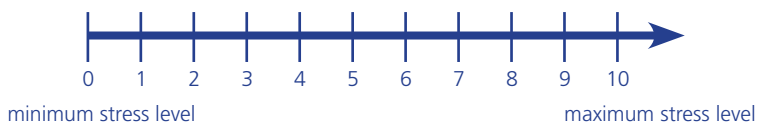
Your own stress management

What are signs of stress, what is constant stress and how can you reduce your own tension?

The principles determining how stress affects the body, what makes us feel stressed, and how stress is experienced are similar to those of pain. First, stress triggers are evaluated (through personal experiences, personal constitution and predisposition, attitudes, capabilities of dealing with stress, etc.). Only then the stress reaction follows in the form of bodily reactions, feelings, thoughts, and behaviours. Stress is part of everyday life. Our bodies are usually able to handle it well: After a period of tension follows relaxation, and the body returns to baseline. If stress stimuli are recurring, the body is stopped from returning to normal: It reduces the tension level, but it never decreases

to the level prior to the last stressor. If the cycle is not interrupted by helpful techniques, constant stress might be the result (-> see above: vicious cycle of pain). Signs of constant stress include: **bodily**: e.g. palpitations, sweating, breathing difficulties, sleep disturbances and chronic fatigue, stomach-, headache and back pain, loss of appetite, or muscle tension; **feelings** such as irritability, nervousness, anxiety, and uncertainty; **thoughts** circling around one topic, concentration difficulties, or mental emptiness may occur. An increased level of stress becomes apparent in **behaviour** through e.g. aggressiveness, being unable to listen, letting social relationships slip, or engaging in an unhealthy lifestyle.

How stressed do **you** feel prior to the dressing change?
How intense is your stress level?



It is helpful to know your stress signs (on a physical, emotional, mental, and behavioural level), in order to engage in timely stress management. Once you

have reached a high level of stress, it is difficult to think clearly and to change your usual behaviour.

What you can do

What are your stress signals?

Physical	X	Emotional	X	Mental	X	Behavioural	X
Palpitations?		Nervousness?		Thoughts circling?		Aggressive behaviour?	
Chest tightness?		Restlessness?		Concentration difficulties?		Fidgeting?	
Breathing difficulties?		Irritability?		Daydreaming?		Shaking?	
Chronic fatigue?		Anger?		Nightmares?		Grinding teeth?	
Stomach ache?		Anxiety?		Mental emptiness?		Not being able to listen?	
Headaches?		Panic?		"I can't do it any longer."		Letting social relationships slip?	
Back pain?		Feelings of failure?		...:		Unhealthy lifestyle (littler exercise, alcohol, smoking etc.)?	
Loss of appetite?		Uncertainty?		...:		...:	
Muscle tensions?		Inner emptiness?		...:		...:	
Heavy perspiration?				...:		...:	

There are several ways to reduce your own stress level, some of which you are already familiar with, as they appeared earlier in the section about pain management for children. Besides relaxation exercises, thought exercises, and the "emergency kit", having open and honest conversations with people you are close to or with supportive health professionals may be helpful to reduce

your stress levels. It could also be helpful to consider finding a balance in your lifestyle, taking care of yourself, having an open and hopeful attitude, and most of all: not carrying the responsibility by yourself.

On the next page you will find the **possibilities for your own stress management** at a glance:

Positive attitude:

- Weighing up, which is the lesser of two evils: e.g. *"We gladly prick blisters caused by fun activities!"*
- Courage to pursue your own path: There is no one right way to handle the situation! Always try new ways.
- Being confident when dealing with doctors, nurses, offices, but also in your social environment.
- Trying to stay open and adaptable (changes in skin condition, changes due to regular developmental changes of your child, altered family situations...).

Support through additional persons:

- Sharing responsibilities! Allow "teamwork", even in – or possibly precisely because – everybody deals with the situation differently.
- Open and honest conversations about your experiences
- Utilizing professional help (counselling, psychotherapy, etc.)

Don't forget about your own life:

- Allow time for yourself, create personal space.
- Strike a balance, create "oases" in everyday life – "what would comfort and strengthen me?"
- Support positive social contacts
- Do have your own interests, e.g. sport, singing, dancing ...

(Regular) relaxation exercises:

- Breathing exercises
- Muscle relaxation (flexing, relaxing, and feeling the relaxation; taking a journey through your body)
- Humour
- Exercise

Mental exercises:

- "Stop sign method" – controlling your thoughts
- Positive instead of negative thoughts
- Positive and encouraging self-instructions
- ...

How the situation can be created to be less stressful

– and why your child thereby experiences less pain during dressing changes

The more pleasant and positive the situation surrounding the dressing change is experienced by the child, the less their attention will be focused on the pain. The important message here is:

Everything is well prepared, and the atmosphere is relaxed.

In the following you will find several tips in form of a checklist:

Checklist

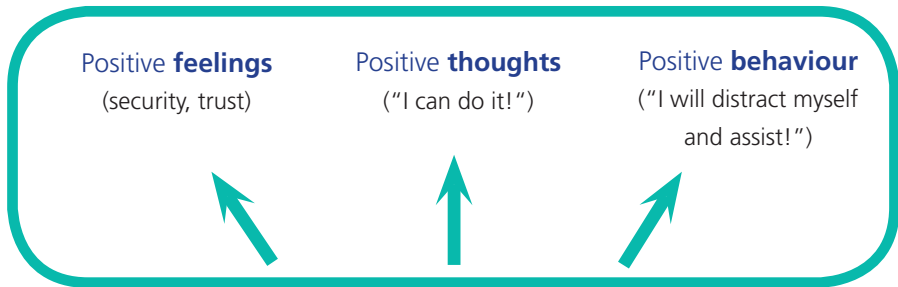
Timing	✓	Room and dressing materials	✓
Planning: <ul style="list-style-type: none"> • Did you inform your child about the upcoming dressing change well in advance? • Have you jointly decided on the time? 		Room: <ul style="list-style-type: none"> • Preheated? (heating lamp?) • Is draught preventable? • Suitable for children? Stimulating? 	
Beginning: <ul style="list-style-type: none"> • Did you stick to the agreed-upon time? No delay? 		Dressing materials: <ul style="list-style-type: none"> • Customized? • Sufficient materials at hand? • If necessary, spare material at hand? 	
Accomplishment without interruptions: <ul style="list-style-type: none"> • Do you have sufficient time on your hands? • Phone on silent? • Additional people responsible for younger siblings? 		Ointments: <ul style="list-style-type: none"> • Preheated? • At hand? 	
Conclusion: <ul style="list-style-type: none"> • Allowing for sufficient time for closing rituals, pleasant activities, and breaks? 		Deposit: <ul style="list-style-type: none"> • Trash for used dressings? 	

These tips for facilitating a pleasant experience during dressing changes might sound simple - there will certainly be days in which, despite great preparation and a relaxed atmosphere, none of the utilized ideas will help. Don't be discouraged! Not every day will be this difficult. Things that don't work out today might work out well tomorrow. If there are changes that you want to make, start with only one thing. Do not change too much at once. And always remember: Teamwork helps! Distribute duties and responsibilities!

For your child	✓	For you?	✓
If applicable: Joint decisions and planning: <ul style="list-style-type: none"> • Time point • Strategies for stress management • Ideas for distraction • "Emergency kit" • Closing rituals 		For you: <ul style="list-style-type: none"> • Previously plan something that you can look forward to. • What gives you strength? Try to set aside stress, all negative thoughts, and tension -> apply breathing exercises and foster positive thoughts. 	
Laundry: <ul style="list-style-type: none"> • Preheated towels, blankets and clothes • At hand? 		Prior relaxation: <ul style="list-style-type: none"> • Calmly enter the situation surrounding the dressing change – communicate calmness. 	
Distraction and relaxation materials: <ul style="list-style-type: none"> • At hand? • "Emergency kit" 		Relaxation during the dressing change: <ul style="list-style-type: none"> • What does your "emergency kit" contain? 	
		For your child: <ul style="list-style-type: none"> • How can you encourage your child today? • What can you praise your child for? 	
		Positive conclusion: <ul style="list-style-type: none"> • Emphasize what went well during the dressing change. 	
		<ul style="list-style-type: none"> • Don't forget to reward both of you for your good work with a fun activity. 	

The most important information at a glance:

Pain during dressing changes can be attenuated by **POSITIVE** factors!



Possible ways to influence the pain:

✓	What your child can do (more or less age-dependent):
	Taking control and influencing the situation: Assisting during the dressing change, taking part in decisions, planning the "emergency kit"
	Encouraging themselves
	Actively coping with stress, anxiety, and pain: relaxation exercises, distraction, mental exercises, "helpers"
	Infants and toddlers need a second person, who can help to focus their attention on the distraction
✓	What you (parents/carer) can do during the dressing changes:
	Emotionally support, encourage, and praise the child
	Instruct the child concerning their assistance, distraction, relaxation, and mental exercises
	Recognize your own stress level, and work on reducing it
	Share responsibilities
✓	With regard to the situation surrounding the dressing change:
	Good preparation
	Create a relaxed atmosphere, and provide a "good" conclusion
	If necessary, include additional people

Take a look at your dressing change

	Prior to the dressing change	During the dressing change	After the dressing change
<i>What works well?</i>			
<i>What is difficult?</i>			
<i>Which new possibilities or ideas might be suitable?</i>			

Further Information

We have summarized all relevant information included in this brochure on a two-paged information leaflet also including a range of strategies. You can access and download the information leaflet and this brochure through this link:

www.kinderpalliativzentrum.de/

Additionally, we recommend the video **“Living with Epidermolysis bullosa – Dealing with pain during dressing changes”**, which illustrates the information conveyed in the brochure on the example of an affected family. You can find the video following this link:

<https://www.deutsches-kinderschmerzzentrum.de/en/about-us/videos/epidermolysis-bullosa-english/>



In closing, we would like to share with you the following quote by Václav Havel*:

**“Hope
is not the conviction
that something will turn out well
but the certainty
that something makes sense
regardless of how it turns out.”**

* Václav Havel, Karel Hvizdala (1990) *Disturbing the Peace: A Conversation with Karel Hvizdala*. Vintage



The German Paediatric Pain Centre



The **German Paediatric Pain Centre** offers children and adolescents with chronic pain comprehensive medical and psychological care consisting of

- medical and psychological pain diagnostics,
- individually composed treatment plans,
- integrative pain therapy procedures such as transcutaneous electrical nerve stimulation (TENS), biofeedback etc.

The staff of the German Paediatric Pain Centre is in close collaboration with established

- paediatricians and primary care physicians,
- all paediatric specialties (e.g. Gastroenterology, Neurology, Rheumatology),
- further specialist disciplines (e.g. Orthopaedics, Anaesthesiology, etc.),
- a variety of occupational groups (child and youth psychotherapist, paediatric nurses, physiotherapist dieticians, etc.),
- paediatric nurses, physiotherapist dieticians, etc.), and complementary medical therapists (homeopathy, acupuncture, etc.).

In addition to the outpatient pain treatment, the German Paediatric Pain Centre offers inpatient treatment on the “Lighthouse” ward for children and adolescents who are severely impaired by their chronic pain. These children are attended by an interdisciplinary team consisting of doctors, psychologists, paediatric nurses, educators, social workers, and various other therapists. In the course of a 3-week-program they learn how to apply pain management strategies. Medical services such as physiotherapy, psychomotor therapy, art and music therapy, chaperoned work shadowing of families in everyday clinical practice, stress tests, and the attendance of the in-house school round off the inpatient therapeutic concept.

In July 2008, the **“Chair for Children’s Pain Therapy and Paediatric Palliative Medicine”** was established at the University of Witten/Herdecke, where numerous research projects focusing on chronic pain in children and adolescents are conducted.

The Paediatric Palliative Care Centre



The **Paediatric Palliative Care Centre**, founded in 2010 at the Children's' and Adolescents' Hospital in Datteln, provides comprehensive treatment for terminally ill children, adolescents, and young adults. The team includes doctors, nurses, psychologists, and educationalists. The treatments aims are to alleviate the child's dreadful symptoms and to enable a life characterized by autonomy and dignity for the families.

The Paediatric Palliative Care Ward "Rays of hope" consists of eight homey single bedrooms including disabled-friendly bathrooms. Wooden furniture hides the necessary technology that supports medical care. These include, among others, an isolator unit, two overhead lifter systems, oxygen, and compressed air connections as well as needs-based central monitoring. Wide glass doors in each room enable direct access – even by wheelchair or hospital beds - to the terrace and the attached sheltered backyard. Medical procedures are conducted in modern treatment rooms and are created to be as pleasant and pain free as possible.

The big "room of life" enables interactions between families, shared meals, and activities. Siblings are able to handcraft and play close to their families. The adjacent Snoezel room with its pillars of colourful bubbles, the waterbed, light effects, and soft music stimulates the senses and promotes relaxation. Fragrant scents awaken beautiful memories and animate to dream.

The admission to the ward "Rays of hope" occurs during times of crisis, making care at home no longer feasible at that time, due to e.g. acute complications or highly complex combination of symptoms. Five family apartments and a family and guest house enable the entire family to be with their child during their stay without further costs.

The average duration of a hospital stay in the Paediatric Palliative Care Centre is three weeks. We aim to enable the children to return to their home environment with the best possible quality of life, in order to allow them to maintain their usual lifestyle for as long as possible.

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