

PAIN

Pain is a daily consideration for a person with EB and can have a large impact on their quality of life. Many factors contribute to pain including: what the person thinks, how they behave and how they feel about pain. Patients may experience a variety physical and psychological effects.

Acute Pain



- Unpleasant sensation that serves as an alarm – designed to protect the body from injury. Acute pain exists so that the body is alerted to the source of injury and can quickly take steps to remove the body from the injury.
- If a part of the body is hurt, pain will alert the person to be cautious with that area so that it can heal.

Chronic Pain



- Pain that lasts longer than 3 months is considered chronic.
- Pain may be continuous – felt all the time or intermittent – comes and goes.
- Sometimes the result of sensitization of the nerves – pain is felt even when there is no injury or danger and the tissue has healed (false alarm).
- Chronic pain can affect mood, sleep, activities of daily living, and quality of life.




Assessing Pain





- Assess pain regularly – this is essential so that an appropriate treatment plan can be developed.
- PQRSTU can be helpful in guiding questions in order to thoroughly assess pain:
 - P = Provoking factors
 - Q = Quality – what does it feel like?
 - R = Does it radiate anywhere?
 - S = How strong is it?
 - T = Is there a time that it is worse?
 - U = What are your thoughts about your pain?
- Assessing pain in children can be challenging. The way children are asked about pain may direct them to an answer. For example, asking “that doesn’t really hurt, does it?” may cause the child to under-report pain. If the child is not asked about pain, she may say nothing even though she has pain. Conversely, frequently asking about pain can increase child’s focus and attention on pain.
- 3 helpful methods:

Method	Comments
Self-report	Can only be used if the child can respond verbally or if they understand the concept and can point to images or numbers <ul style="list-style-type: none"> • Do you have a hurt/”owie”/pain? • Can you show me where it hurts? Does the hurt go anywhere else on or in your body? • When did the hurt start? How long has it been there?

PAIN

<div>Assessing Pain</div> <div></div>	<div><div><div></div><div></div><div></div></div><div><ul style="list-style-type: none">Do you know what might have started it?How much does it hurt? (Example 1, Numeric Rating Scale - on a scale of 0 to 10, 0 meaning no pain and 10 meaning severe pain, how strong is your pain? Example 2, Faces Pain Scale)What helps to take away the hurt? (Medicines you’ve had before, heat/cold, playing with your friends?)</div></div> <div><div>Observer report</div><div><ul style="list-style-type: none">Changes in facial expression, body movements, and cry may all indicate pain.FLACC © is a useful tool to help determine pain (see end of document).</div></div> <div><div>Physical changes</div><div><ul style="list-style-type: none">Pain can be assessed by measuring changes in the body’s physiological responses.Increased heart rate, blood pressure, breathing rate, and presence of sweating can be caused by pain.Reserve this assessment method for times when other methods cannot be used.</div></div>
<div>Factors Influencing Pain</div> <div></div>	<div><ul style="list-style-type: none">The emotional context that the patient experiences pain is extremely important. Some people may be depressed, confused, worried, frustrated or angry about their pain. These emotional factors can have an impact on the amount and intensity of pain.Adults and Children may not want to talk about their pain. Children are sometimes taught that they should endure pain and that crying is a sign of weakness. These beliefs, which can apply to all cultures and ages and to all genders, may affect the way the patient expresses and reports pain.A child may play down the extent of pain to please her parent or other caregivers. Children may also play down the extent of their pain out of fear. Your child may think that if she reports her pain as severe, she will have to stay longer in the hospital, away from her family, friends, and home.Before assessing pain, let them know that it is important to be honest about their pain so that you can help. The patient should feel they are part of the process of pain assessment and relief.</div>
<div>Treating Pain: Psychological Strategies</div> <div></div>	<div><ul style="list-style-type: none">Because emotion affects pain, the way a parent speaks can have a great influence on how their child responds to pain. The language that parents use should be as hopeful as possible and should not contain anything that your child might consider judgmental or doubtful.Acknowledging the adult or child’s pain, and being honest about what is happening, may help to reduce the distress and intensity of the pain.</div>

PAIN

	<ul style="list-style-type: none"> Patients can be taught relaxation techniques to help them cope with pain. Breathing, imagery, visualization and distraction, are all helpful pain-coping strategies. Other techniques such as mindfulness meditation and cognitive behavioral therapy have been shown in research to greatly help with chronic pain. 								
Treating Pain: Physical Strategies 	<ul style="list-style-type: none"> Physical therapies typically consist of methods such as heat, cold, touch and exercise but must be tailored to individual needs of person with EB. Making adjustments for maximum pain relief requires re-assessment and a certain amount of trial and error in terms of finding strategies that work best for the patient. Health care pain experts are important members of the interdisciplinary team – they can help tailor treatment regimens that work best for the patient. 								
Special Considerations 	<ul style="list-style-type: none"> Medication for pain relief should be prescribed by the EB expert team, pain specialist, or Most Responsible Health Care Provider. Any questions about medication should be directed to either the Pharmacist or prescriber. There are many specific pains or discomforts that may be experienced by a patient with EB. <table border="1"> <thead> <tr> <th>Consideration</th><th>Comments</th></tr> </thead> <tbody> <tr> <td>Bathing and Dressing changes</td><td> <ul style="list-style-type: none"> Bathing and dressing changes are often painful, anxiety provoking experiences for children with EB. Pain medications and psychological strategies (e.g. Distraction, visualization, breathing exercises) should be used to prevent and minimize pain and fear. Pain medications may be taken by mouth (oral) or applied to the skin (topical) and may be given 20-30 minutes before the wound care routine It is important to involve children in their care as much as possible. For example, allow them to help prepare dressing change materials, and to control for environmental factors that may be affecting pain (e.g. Reduce drafts, keep room warm). For older children and adults cognitive behavioral techniques are strongly encouraged. </td></tr> <tr> <td>Pain in GI tract</td><td> <ul style="list-style-type: none"> The gastrointestinal tract of patients with EB is often a source of discomfort. Ulcerative lesions, acid reflux (gastroesophageal reflux disease), chronic constipation and esophageal strictures are the most common causes. Prevention is very important: a gastroenterologist and dietitian are often members of the health care team. Topical pain medication such as analgesic mouth rinses have shown to be helpful for mouth pain. </td></tr> <tr> <td>Joint and Bone pain</td><td> <ul style="list-style-type: none"> Often a physiotherapist and occupational therapist are members of the team to help develop strategies to reduce pain with ADLs and physical activity. </td></tr> </tbody> </table>	Consideration	Comments	Bathing and Dressing changes	<ul style="list-style-type: none"> Bathing and dressing changes are often painful, anxiety provoking experiences for children with EB. Pain medications and psychological strategies (e.g. Distraction, visualization, breathing exercises) should be used to prevent and minimize pain and fear. Pain medications may be taken by mouth (oral) or applied to the skin (topical) and may be given 20-30 minutes before the wound care routine It is important to involve children in their care as much as possible. For example, allow them to help prepare dressing change materials, and to control for environmental factors that may be affecting pain (e.g. Reduce drafts, keep room warm). For older children and adults cognitive behavioral techniques are strongly encouraged. 	Pain in GI tract	<ul style="list-style-type: none"> The gastrointestinal tract of patients with EB is often a source of discomfort. Ulcerative lesions, acid reflux (gastroesophageal reflux disease), chronic constipation and esophageal strictures are the most common causes. Prevention is very important: a gastroenterologist and dietitian are often members of the health care team. Topical pain medication such as analgesic mouth rinses have shown to be helpful for mouth pain. 	Joint and Bone pain	<ul style="list-style-type: none"> Often a physiotherapist and occupational therapist are members of the team to help develop strategies to reduce pain with ADLs and physical activity.
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PAIN

		<ul style="list-style-type: none"> Staying active helps maintain bone health and reduce pain. 	
	Eye pain	<ul style="list-style-type: none"> Eye pain in EB is usually caused by corneal abrasions Comfort measures such as avoiding bright light, lubricating eye drops and mild pain medications such as Acetaminophen and Ibuprofen, should be considered as needed. 	
	Infants and very young children	<ul style="list-style-type: none"> For children with severe forms of EB, pain often starts immediately. Health care providers will use pain measurement scales specially developed for infants. A prescribed sugar solution called Sucrose can be used alone or together with other pain medications and other comfort measures such as swaddling, music, gentle rocking, may be used to prevent and reduce pain from procedures (such as dressing changes and bathing). 	
	Pruritus (Itch)	<ul style="list-style-type: none"> Itch is often the most bothersome symptom with EB. There are several preventive measures that can be taken such as: drinking enough fluids and good skin care to prevent dry skin, good nutrition to promote healing, avoiding irritants (e.g. rough clothing) and scratching (short nails, covered skin) and avoiding overheating. Cognitive behavioral therapy can also be helpful to reduce scratching behaviors that may become a habit. Some pain medications, such as opioids, can also cause itch so it is important to balance pain relief with possible side effects. 	
	Post-operative	<ul style="list-style-type: none"> Children with EB may need to have operations related to their diagnosis or for an unrelated reason. It is important that a pain management plan (for before, during and after the operation) is discussed and developed ahead of time with your healthcare team. 	

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Behaviour	0	1	2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant quivering chin, clenched jaw
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting, back and forth, tense	Arched, rigid or jerking
Cry	No cry (awake or asleep)	Moans or whimpers; occasional complaint	Crying steadily, screams, sobs, frequent complaints
Consolability	Content, relaxed	Reassured by touching, hugging or being talked to, distractible	Difficult to console or comfort

Disclaimer: Unless stated otherwise, information contained in this document is taken from Epidermolysis Bullosa: A Handbook for EB Patients and Families, Developed by the Section of Dermatology at the Hospital for Sick Children with the Support of DEBRA Canada and Sick Kids Hospital Department of Dermatology EB Expert Team - all content used with permission. This document was created by SWRWCP (August, 2019)