
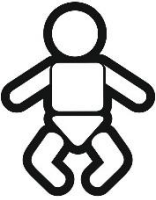




PSYCHOSOCIAL


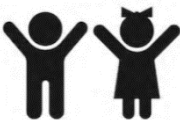

Living with EB and trying to live a normal life can be challenging and come with both success and failures. Every form of EB and every person living with EB has a special set of challenges¹. Patients have unexpected medical appointments and/or needs, illness can exacerbate problems¹. Having a general understanding of some of the challenges a person with EB and their caregivers may face can help facilitate open communication and allow for the health care provider to provide support¹.

<p>Initial Diagnosis</p> 	<p>It is often overwhelming for parents to learn that their child has EB.</p> <ul style="list-style-type: none"> • Everyone reacts differently and can experience a range of emotions and may experience stages of grief. • Support mothers and assess for post-partum depression. • Multiple unknowns for the family which can create fear. • Be supportive and provide family with resources about EB, encourage questions. • Family may feel overwhelmed with multiple medical appointments – help family prepare, make lists of questions. • Encourage membership to DEBRA Canada – helps build support network.
<p>Newborn Stage</p> 	<ul style="list-style-type: none"> • Attachment is crucial between the caregiver and newborn – helps newborn feel safe and is important for future relationships for newborn – encourage positive physical contact (hugging, holding, kissing, face-to-face.) • Encourage caregivers to not be afraid to hold and touch the baby. Modifications that will be needed: <ul style="list-style-type: none"> ○ Do not pick baby up by underarms ○ Use soft blanket under the baby ○ Pat instead of rub the baby • Determining what products work best for the baby will be a trial and error process – be supportive and reach out to EB expert team with questions.
<p>Pre-School Stage</p> 	<ul style="list-style-type: none"> • Children are exploring their environment – learning how to sit and crawl. • Blisters will develop in areas where friction occurs – medical team can help with bandaging techniques to minimize friction. • Parents will want to protect their children from injury or pain – However, blisters cannot be completely prevented and it is important for the child to explore in order to achieve developmental and social milestones.
<p>School Age</p> 	<ul style="list-style-type: none"> • Caregivers may have fears around their child entering the school system. • Refer to the section regarding school for more detailed documents/education. • Encourage partnerships with the school including meetings to discuss needs and safety plans. • It is important to discuss learning plans – children with EB may have increased absences due to illness or medical appointments. • Encourage open communication with the child about their diagnosis. Equipping them with the tools, knowledge, and confidence to answer people's questions when asked about their disease.

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).

1. Diem, A. 2009. Living with EB – Impact on Daily Life. IN: Fine JD, Hintner H (eds.), Life with Epidermolysis Bullosa (EB). Etiology, Diagnosis, Multidisciplinary Care and Therapy. Springer, Wien, New York, (2009): ISBN 978-3-211-79270-4.

PSYCHOSOCIAL

	<ul style="list-style-type: none"> Prompting independence is important for the development of healthy self-esteem. 						
Adolescence and beyond 	<ul style="list-style-type: none"> This can be a challenging time as body image and relationships become a high priority. Physical limitations may prevent the patient from participating in activities with peers. Encourage hobby development – beneficial to confidence and self-esteem. Promote independence – sense of control over their life. Encourage adolescents to participate in their medical care and medical decisions. Stress the importance of regular skin checks by the medical team for early detection of cancerous lesions. *Regular medical monitoring helps early detection of squamous cell carcinoma – a serious medical concern. 						
Siblings 	<ul style="list-style-type: none"> Siblings may feel “left out” or that they are not getting attention – encourage one-on-one time with the caregiver. Feelings of anger or jealousy may occur – important to know that this is common feeling for siblings – talk to them about EB and how it affects their sibling. Speak openly and honestly and dispel worry and concern when able. 						
Talking to a child with EB 	<ul style="list-style-type: none"> It is important to encourage and support open, early, and age-appropriate conversation with the child about their diagnosis. Often times the child can sense that something is wrong. Use simple terminology to discuss EB. Stress that EB is not contagious. Encourage them to ask questions at their medical appointments and to talk about how they are feeling. <p>Common questions:</p> <table border="1"> <thead> <tr> <th>Question</th><th>Answer</th></tr> </thead> <tbody> <tr> <td>Why me?</td><td>No one knows why but we know that it is no one's fault.</td></tr> <tr> <td>Will I get better?</td><td>EB does not go away, this is why you go see the doctor and do things at home to try to make EB as manageable as possible.</td></tr> </tbody> </table>	Question	Answer	Why me?	No one knows why but we know that it is no one's fault.	Will I get better?	EB does not go away, this is why you go see the doctor and do things at home to try to make EB as manageable as possible.
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Why me?	No one knows why but we know that it is no one's fault.						
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Useful Websites/links: <ul style="list-style-type: none"> www.swrwoundcareprogram.ca EB Resources, including EB handbook: https://www.debracanada.org 							

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