



PSYCHOSOCIAL

Support for adults living with epidermolysis bullosa (EB)

**This is how life feels
to people with EB.**



WHAT IS EPIDERMOLYSIS BULLOSA?

EB is a group of rare genetic disorders characterised by fragility of the skin and mucous membranes and mechanically induced blistering. EB comprises four main types - EB simplex (EBS), junctional EB (JEB), dystrophic EB (DEB), and Kindler EB (KEB), with more than 30 subtypes. EB is clinically heterogeneous including a broad spectrum of severity.

**Cover photo: Ingrid Vitória Aparecida Martins, living with recessive dystrophic EB, aged 24, Brazil
(photo credit: Suelen Szymanski)**



Emanuel Kluge, living with recessive dystrophic EB, aged 18, Brazil (photo credit: Suelen Szymanski)

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Artwork by Kristina Gligora, born with recessive dystrophic EB generalised severe, (1992–2019), Croatia

What is psychosocial support?

Psychosocial support means helping to support psychological, social, emotional, and spiritual well-being. This is formed during a person’s lifetime and is influenced by environmental factors as well as factors that are unique to each individual.

Who is this booklet for?

This booklet is for adults (16+ years old) living with any of the following types of EB:

- ▶ EB simplex (EBS)
- ▶ dystrophic EB (DEB)
- ▶ junctional EB (JEB)
- ▶ Kindler EB (KEB)
- ▶ EB acquisita (EBA) - autoimmune, not genetic*

*There was no evidence found in this population group for the CPG. However, it is assumed that they would require the same support.

What is this booklet about?

This booklet provides information on psychosocial support for people living with EB.

Topics covered in this booklet include:

- ▶ wound care and pain management
- ▶ self-advocacy and independence
- ▶ life stages and transitions
- ▶ when to get help
- ▶ EB team/healthcare provider help

Where does the information in this booklet come from?

The information and recommendations in this booklet are derived directly from the “Psychosocial recommendations for the care of children and adults with epidermolysis bullosa and their family: evidence based guidelines”. The guidelines were written in 2018 by a group of EB healthcare professionals, individuals living with EB, and family members. The information and recommendations in the guidelines come from a variety of sources including clinical research and expert opinion.

There are three different types of recommendations in this booklet:



STRONG RECOMMENDATION
based on good-quality
research evidence



RECOMMENDATION
based on research
evidence



RECOMMENDATION
based on clinical
experience



This icon signposts to recommendations that overlap with those from other EB clinical practice guidelines (CPGs). These are referenced to on page 25.



“ For some people EB can take so much time having baths, changing dressings etc. One of my dearest friends living with RDEB demands much more care and time. She told me that she viewed caring for EB as her work, ‘I get up in the morning, the nurses come, I view them as work colleagues, and the EB routine is a job. This helps to manage EB and not to be so frustrated at the time it takes.’ That is very clever, I learned a lot from knowing my friend. ”

Judith Kristin Asche (right), living with junctional EB non-herlitz, aged 57, Norway

Pain is an inevitable part of living with EB. When that pain is not managed well it can seriously impact your social and emotional health. Not only is pain management important in order to feel better physically, it can also help you feel better emotionally. For many people with EB, medications are necessary and help to manage this pain (see the pain management CPG). These recommendations are additional, non-pharmacological techniques that can be beneficial, particularly during wound care. You may have other techniques that work for you. The important thing is to have a plan for how you can work towards decreasing the pain you feel during wound care as well as throughout daily life.

Anxiety appears when we feel we are not in control of a situation and can get worse when we have had negative experiences in the past. Bandage changes and baths are a prime example where the level of anxiety experienced can be very high. Although anticipatory anxiety (anxiety you experience when thinking about a future situation) can increase the perception of pain, this actually means you can manage the amount of perceived pain yourself by coping with the anxiety. To cope with anxiety, it is very important that you control the speed of bandage changes and baths by deciding where, how, and how quickly or slowly you wish to proceed. If you have someone helping you with wound care, it is beneficial that he or she keep you informed about their actions and consult on these with you. This will help you feel in control of the whole procedure by anticipating the following steps and ensuring your comfort.



Tips during bandage changes

- ▶ Use distractions and take part in pleasurable activities to reduce anxiety (listening to music, singing, watching TV or films, eating, or meditating).
- ▶ Remember that you are in control of where, how, and how quickly or slowly you wish to proceed with bandage changes.
- ▶ If you have someone helping you with your wound care, discuss each step before it happens.
- ▶ Engaging in bandage changes will also help reduce pain.



Your EB team/healthcare provider can:

- ▶ explain why pain management is important
- ▶ discuss any doubts you may have in using pain medication
- ▶ offer effective approaches to manage chronic and acute pain (see the pain management CPG)
- ▶ make a personal pain plan, especially if there are serious wounds.

Be sure to make your pain management a priority. If pain is interfering with any part of your life (school, work, family, socialising), then think about talking to your EB team/healthcare provider. Even for people who take pain medication, additional pain management strategies can be very useful. As you know, living with some amount of pain is inevitable, but ideally getting to a point where managing the pain to an acceptable level (for you) can limit the impact that pain has on your own psychosocial well-being.

Recommendations

- ▶ Get psychosocial support to help with your pain management.
- ▶ Discuss pain management with your EB team/healthcare provider to help you cope with treatment/wound care-related pain.
- ▶ Get psychosocial support to improve your well-being as physical pain can affect your psychological well-being, mood, and behaviour.



Strong recommendation from the pain management CPG

Pain can be persistent (chronic) or acute (such as when you change bandages). Because mental and physical health are linked, it is important to discuss psychological ways of managing your pain.



“ The most important thing is to be open about your diagnosis and to talk about it. Find others who have EB because then you don’t have to feel alone, others will understand. You have got to get used to explaining EB to people, but it is nice to not have to. ”

Kari Anne Bø, living with EB simplex Ogna, aged 36, Norway

Many people with EB are fortunate to have the love and support of family and friends who help care for their medical needs, but as you get older advocating for yourself is an important milestone to reach for. Whether or not you have caregivers who are currently playing an active role in your life, it is never too early to start thinking about how to be as independent as possible. Being your own advocate is a good way to start becoming more independent. Moving towards some level of independence can lead to improvements in your psychosocial well-being.

These are some things to consider as you think about advocating for yourself:

- ▶ Remember you are not alone even though it can often feel like that.
- ▶ Consider reaching out to connect with others who are living with EB. Whether it is through social media or in person, knowing you are not the only one going through everything that comes with having EB can be empowering. It can also provide you with a level of support and understanding that you may not get from your family/friends who do not have EB.
- ▶ You could also reach out to people who may be living with another kind of physical condition. Sharing experiences can be empowering and inspiring, and could help you to have a more positive outlook on your condition and life so that you do not feel restricted or defined by EB.

Tip

We cannot emphasise enough how important it can be to connect with others who have EB. Having someone who ‘understands you’ can be incredibly empowering. This is also where you are likely to get the best advice on how to get through whichever life stage you are in.

Recommendation

Find psychosocial support to help you cope with living with EB. This can help you increase your participation in your social life, promote self-management, build your social and communication skills, and promote a positive body image to improve your psychological well-being.



“ Managing EB is about continuing to do activities that you enjoy whilst not being afraid to explore options, to have a go, find out what you are interested in and capable of. I am married, I like to build things, I even have a child. I was told that with recessive EB inversa this was not possible. It is hard but it is possible. Unless you try things you won't know what you are capable of; to have that sense of achievement and develop your own interests and a sense of what you are good at. ”

Ida Steinlein, living with recessive dystrophic EB inversa, aged 31, Norway

Communicate with your EB team/healthcare provider. If you were diagnosed as a child, then it may be your parents who have done most of the communicating for you; however, if you want to play an active role in your own health, make sure you are part of the process: ask questions, and share your own thoughts and ideas with them. This is your life, so if you have not done so already, try to take a more active role.

If EB is making it difficult for you to stay on task at work or at school/university, think about communicating some of your challenges with your superiors/teachers. While no one will ever truly understand what you go through, they are likely to feel empathetic and may help accommodate you according to your needs. For example, if you are in school or university your teacher may be more likely to give you extended time on an exam paper if they know you have just had surgery or are in a lot of pain. **People can't know what you don't share with them.** If you live in a country that has laws that protect people with disabilities, make yourself familiar with those laws so you know what your rights are.

Self-advocacy will help you to cope with the different negatively-perceived effects that you may feel EB has in your life. Some people feel out of control of the limitations EB imposes. This lack of control can mean they feel that takes over, stripping them of their identity. This is normally related to a “passive” rather than an “active” attitude towards EB, and the type of decisions you make to manage and deal with these negatively-perceived effects. Getting to make decisions about your care and the effects EB may have on your routine at different life stages will help you regain and/or strengthen a sense of control over your life and identity. EB cannot be the centre of your life and if you start relating to it, rather than feeling restricted by it, you will be the one who gets to decide the direction your life will take and who you want to be, not EB.



“ When I was a child I used to have terrible anxiety about what people may think about my appearance. I had a great experience of joining the Scouts, I had to join in and this really built my confidence. Instead of being averse to active and social situations, I actually enjoyed them. Now I realise that people aren’t so disgusted by EB. It gave me a group of friends who could relate to me as a person, not just seeing my EB. ”

Matt Lightfoot (left), living with dominant dystrophic EB, aged 26, United Kingdom

Most people who have EB are born with it. As a result there are new challenges that come along with having EB in every stage of life. As a young child, you often have your parents to help navigate these stages, but as you get older it will be less about who is providing your care and more about you. It is perfectly normal to think about how EB may impact relationships, such as friendships or romantic relationships. It is also perfectly normal to have concerns about how your body looks compared to someone without EB. Lastly, it is perfectly normal to contemplate whether or not you can handle going to university or work. The important thing to know is that you do not have to do it alone.

Regardless of the severity of your EB, it can be hard in each and every life stage. You may feel alone at times but remember, there are others who have been where you have been or where you are now; if you try to reach out, the journey can often get easier.

Your EB team/healthcare provider can:

- ▶ prepare for the potentially difficult aspects of life stages and transitions
- ▶ ask for support and use professional and other people’s experiences to help guide you and problem solve challenges
- ▶ get support if it is overwhelming - a psychologist, social worker, or other healthcare professional may be able to help.



Recommendations

- ▶ Reach out to other people with EB. This can improve your psychosocial well-being.
- ▶ Identify and prepare for potential challenges. Healthcare professionals and other people with EB may be able to help.



“ It is important to be in a partnership with professionals; we are both experts in EB and we work together. Nobody has all of the answers but we try to figure problems out together. ”

Judith Kristin Asche, living with junctional EB non-herlitz, aged 57, Norway

Sometimes it may be difficult to reach out for help because you may feel it is a sign of weakness, or you are afraid to lose independence or self-determination if you do. It is actually quite the opposite; reaching out for help has the potential to strengthen your own abilities to cope and to deal with what you feel is affecting you.

Of course, you might be thinking that most healthcare professionals do not know anything about EB so what is the point? Or maybe you have reached out in the past and did not feel like you were understood? We are here to tell you it is always worth trying again. If you feel that you could use help with managing your pain, anxiety, depression, or just generally being able to fit in with your friends/classmates/colleagues, there are healthcare professionals who can and want to help you live your best life. Reaching out for help when you need it should be seen as a strength not a weakness.

Below are a few examples of when it might make sense to find professional help:

- ▶ You want to go to university or get a job but do not know how that is even possible given the impact EB has on your life.
- ▶ Your pain is not well controlled and is making it difficult to:
 - concentrate (having difficulty reading books, following conversations, paying attention to films)
 - maintain relationships (fighting more with loved ones, not feeling well enough to socialise with friends)
 - sleep.
- ▶ You are feeling down or have lost interest in your normal activities.
- ▶ You no longer want to leave the house.
- ▶ You feel like your life is not worth living or that people around you would be better off if you were gone.
- ▶ You are having active thoughts of wanting to take your own life (suicide).

If you live in an area where mental healthcare is available, reach out to your EB team/healthcare provider to learn how you can access that care. If you live in an area where that may not be available or you are hesitant to make that phone call, reach out to your national DEBRA group for support or contact DEBRA International.



“ Recently, I’ve moved away from home and married somebody else with EB (RDEB). This has presented further issues, such as worrying about each other’s health as well as just our own. Also, the very real possibility of having to bring up a child or children alone, and how the surviving parent would cope psychologically and with having EB. The introduction of care agencies and social services into my life (providing my husband’s care) and the added restrictions they impose on our life together, as well as the all-consuming focus on our health as at least one of us is always unwell, and a sudden lack of parental support.* ”

**Gemma Jaega, living with recessive EB simplex, aged 28, United Kingdom;
Mike Jaega, born with recessive dystrophic EB (1971-2019), United Kingdom**

If you have access to an EB centre of excellence or a healthcare provider who understands EB, share what you learn from these encounters with others who have EB. Of course, everyone living with EB has a different experience so make sure that your EB team/healthcare provider know how EB is affecting you. Many people, however, live in a country or region of a country where there are few, if any, healthcare professionals who know or understand the many effects EB can have on a person’s life. This can be very frustrating and, in some cases, it may make you feel like it is not worth reaching out for professional help. We acknowledge that this is a very real frustration, but want to let you know that a good healthcare provider is also a good listener. If you find a good healthcare provider who is willing to listen to your story and do some research on their own, they are someone worth working with. They do not need to be an EB expert to help you with pain management, depression, anxiety, or any other EB-related struggle.

Strong recommendation

Request psychosocial care from your EB team/healthcare provider as well as physical medical care.

Recommendation

Work in collaboration with your EB team/healthcare provider to improve your quality of life.

*Since this CPG publication, Gemma’s husband has sadly passed away. There has undoubtedly been a psychological impact not only by the natural loss of a loved one but the fact that his death was due to complications of a condition that they both shared.

Tell us what you think

Have your say in the future patient versions of clinical practice guidelines (CPGs) for epidermolysis bullosa (EB)

The purposes of this survey are to:

- ▶ assess the quality of the information, presentation, and delivery of the patient versions
- ▶ help us to develop a standard for all patient versions now and in the future.

The data collected will help us to improve the information provided and experience of the user in all future CPG patient versions. The data may be used to report the development steps taken to improve their quality; this may be done through conference presentations, posters, abstracts, or studies.

We want to make sure that all patient information provided meets the needs of everyone living with EB.

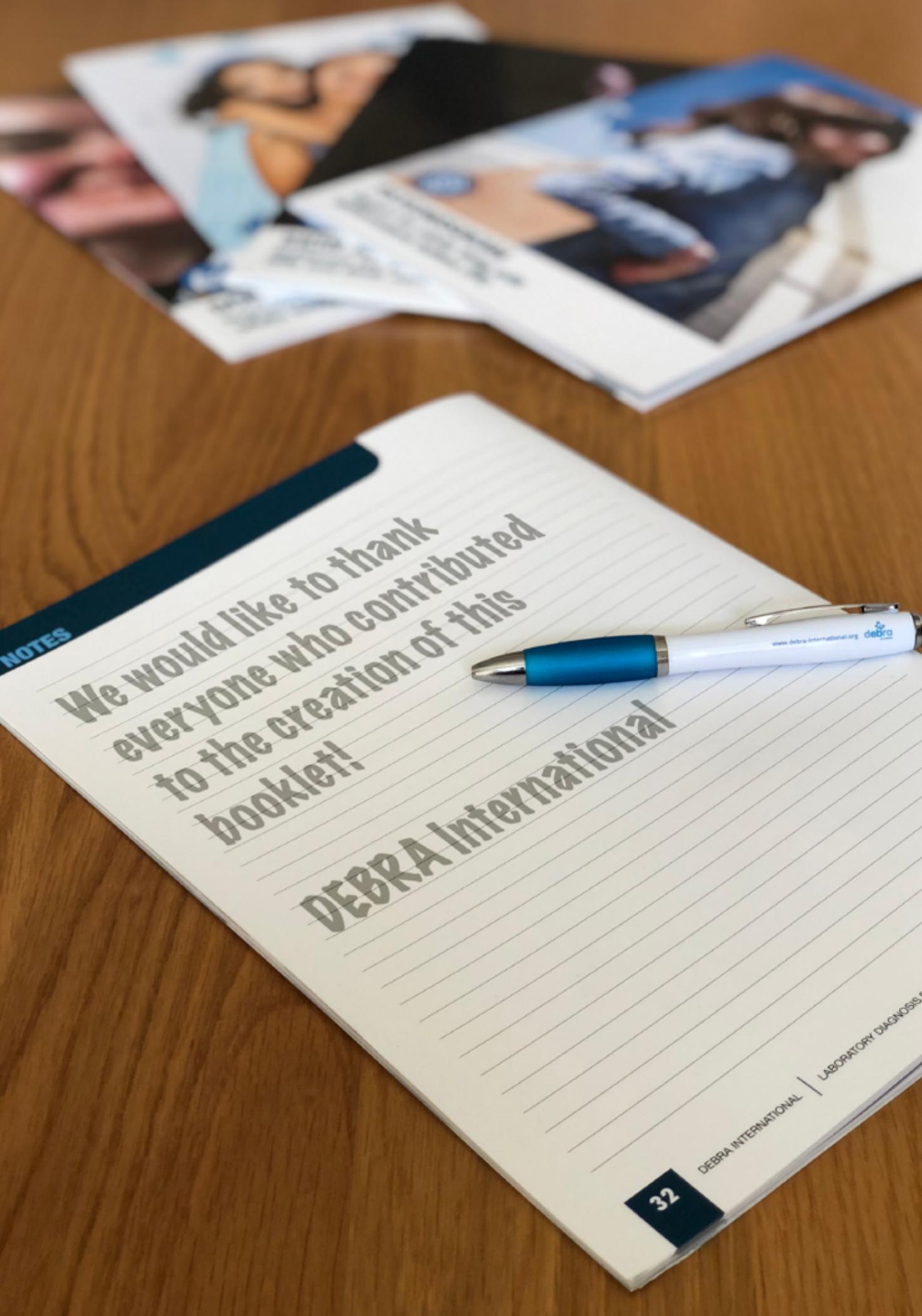
Help us create new CPGs and patient versions

All responses to the above survey are confidential unless you decide to join the DEBRA International CPG network. Please consider joining the network if you are interested in becoming involved in the development of CPGs and patient versions in the future. To join the network, please complete question 1 on page 7. If you do not complete this question, we will not receive any of your personal details and you will remain anonymous. Joining the CPG network is entirely voluntary and you may choose to opt out at any time by contacting DEBRA International.

If you have any questions when completing this survey or about joining the CPG network, please contact the DEBRA International CPG Coordinator, Katty Mayre-Chilton by email at: katty.mayre-chilton@debra-international.org

TELL US WHAT YOU THINK!

Answer the survey to help us improve the patient versions of the CPGs:
www.surveymhero.com/c/PatientVersionsSurvey





Tauani Vieira (centre), living with recessive dystrophic EB, aged 24, Brazil (photo credit: Suelen Szymanski)

Disclaimer

The information contained in this booklet does not indicate an exclusive course of action or serve as a standard of medical care. Variations, taking individual circumstances into account, may be appropriate. The authors of this booklet have made considerable effort to ensure that the information contained within accurately reflects the content of the guidelines on which it is based. The authors, DEBRA Norway, and DEBRA International accept no responsibility for any inaccuracies, information perceived as misleading, or the success of any recommendations, advice, or suggestions detailed in this booklet. The information provided on the following pages is subject to change without notice. For the most up-to-date information on available clinical practice guidelines, booklets, and contact information, please visit: www.debra-international.org

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Development source

Psychosocial recommendations for the care of children and adults with epidermolysis bullosa and their family: evidence based guidelines

This CPG was approved by DEBRA International and funded by DEBRA Norway.

To access the following CPGs and patient version booklets, please visit: www.debra-international.org



Psychosocial booklets

- ▶ Psychosocial support for parents caring for a child living with epidermolysis bullosa (EB)
- ▶ Psychosocial support from your EB team/healthcare provider



Other CPG topics referred to in this booklet

Pain care for patients with epidermolysis bullosa: Best care practice guidelines

Other CPG topics

- ▶ Clinical Practice Guidelines for Epidermolysis Bullosa Laboratory Diagnosis
- ▶ Foot care in Epidermolysis bullosa: Evidence-based Guideline
- ▶ International Consensus Best Practice Guidelines for Skin and Wound Care in Epidermolysis Bullosa
- ▶ Management of Cutaneous Squamous Cell Carcinoma in Patients with Epidermolysis Bullosa: Best Clinical Practice Guidelines
- ▶ Occupational therapy for epidermolysis bullosa: clinical practice guidelines
- ▶ Oral Health Care for Patients with Epidermolysis Bullosa - Best Clinical Practice Guidelines
- ▶ Pain care for patients with epidermolysis bullosa: Best care practice guidelines

Other languages

We are happy to consider requests for this booklet to be provided in other languages. Please send all enquiries to: office@debra-international.org

How was the Psychosocial guideline produced?

- ▶ The CPG development group consisted of EB experts: psychologists, paediatric dermatologists, nurses, a dietitian, a methodologist, and patient representatives.
- ▶ All panel members completed written conflict of interest and code of conduct declarations.
- ▶ During guideline development, the group met twice in face-to-face meetings to discuss the clinical questions and methodology; review the evidence (publications in the field of EB psychosocial research); formulate recommendations; and agree on the guideline's structure and wording.
- ▶ CPGs are based on a critical, extensive, and exhaustive review of the most relevant publications in the field of EB psychosocial research together with the personal experiences of the panel members.
- ▶ To identify publications, 12 electronic search engines were accessed, including Medline (PubMed MeSH), Embase Emtree PsychInfo, CINAHL, Scopus, and the main search engine for the National Institute for Health and Care Excellence (NICE). Searches were performed using the terms "EB and Psychosocial", "EB and psychologist" and "EB and social" in four different languages with the search period ending December 2018.
- ▶ A total of 601 articles were identified. Finally, 36 papers were appraised, each by two panel members, according to the Critical Appraisal Skills Programme (CASP) and Scottish Intercollegiate Guidelines Network (SIGN) quality rating.

Panel group

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