



OCCUPATIONAL THERAPY

Improving participation in daily activities 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.



Emanuel Kluge, living with recessive dystrophic EB, aged 17, Brazil (photo credit: Suelen Szymanski)



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Larissa Miranda Teixeira, living with dystrophic EB, aged 22, Brazil (photo credit: Pedro Mendes/P9 Marketing)

Who is this booklet for?

This booklet is for adults (16+ years old) living with any of the following types of EB who are experiencing limitations in their daily activities:

- ▶ 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 improving participation in daily activities for adults living with EB. Topics covered in this booklet include:

- ▶ what is an occupational therapist and what do they do?
- ▶ activities of daily living (ADLs)
- ▶ instrumental activities of daily living (IADLs)
- ▶ using your hands
- ▶ fine motor skills
- ▶ oral feeding skills
- ▶ how your occupational therapist can help

Where does the information in this booklet come from?

The information and recommendations in this booklet are derived from the “Occupational therapy for epidermolysis bullosa: clinical practice 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 is one type of recommendation in this booklet:



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 27. This patient version also has additional examples to help users understand the variety of tools or equipment they can seek.



What is an occupational therapist and what do they do?

An occupational therapist (OT) helps people to improve their participation in daily activities. They can find ways to change an activity, an environment, or a person's abilities to make participation possible. Living with EB means you can experience barriers to participating in the activities you value.

An OT helps to:

- ▶ assess your daily activities (personal care, eating, education and work, leisure and social activities, and care needs)
- ▶ advise and provide suitable equipment for home, school, the workplace, and other environments
- ▶ do an assessment of hand function and advise on (custom-made) splints
- ▶ provide advice for work places.

An OT can be a life-changing resource. It is important to remember that ideally an OT works with a multidisciplinary team (MDT) including doctors, dietitians/nutritionists, psychologists, physiotherapists, speech and language therapists, social workers, other medical professionals, and, most importantly, with you.

The medical team must work together to find safe solutions that work for you as an individual, your body, and your life.

Vanderson de Jesus Silva, living with recessive dystrophic EB, aged 28, Brazil (photo credit: Suelen Szymanski)





“ I can’t walk very well, can hardly hold a pen due to my fingers fusing together... I was able to attend school, graduated from college, passed my driving test, and found my ideal job as a web designer. I felt in control of my condition and my life. ”

Stief Dirckx, born with recessive dystrophic EB, (1978-2018), Belgium

Activities of daily living (ADLs) are basic activities performed by people on a daily basis that are necessary for independent living. These are activities that are needed to take care of your body that are fundamental to living in a social world, enabling basic survival, and well-being.

OTs teach and rebuild the skills people need to maintain, regain, or increase their independence in all ADLs. These activities include bathing and showering, toileting and toilet hygiene, dressing, eating and feeding, and personal hygiene and grooming.

An OT can help you to become more independent by changing the set-up of your environment, the way you do tasks, or the equipment you use to be able to do these tasks.

Everyone’s needs are different.

Recommendation

If you are experiencing limitations in self-care or decreased mobility, work together with your OT (and/or MDT) to improve your abilities and quality of life. Working with your OT (and/or MDT) can help you to get appropriate modifications, adaptations, and recommendations of equipment to help your independence.

There are several types of helpful equipment. The following are some examples but your options are not limited to these alone. Work with your OT (and/or MDT) to find out what is locally available and appropriate for you. You should also receive periodic monitoring of your progress.

Toileting and toilet hygiene

- ▶ Toilet chairs will improve independence by providing additional support to sit down on and get up from the toilet.
- ▶ Soft raised toilet seat cushions or comfort raised toilet seat foam can be used to provide a more comfortable position on the toilet.

Bathing and showering

- ▶ Bath chairs protect the skin from being damaged and allow for safety in the bath or shower.
- ▶ Motorised bath seats or inflatable bath cushions that can deflate can gently lower you into the bath.



Recommendation from the skin and wound care CPG

Do not hold the shower head directly above the skin as this can hurt and damage it. Pour the water onto a sponge and allow it to trickle onto your body.



Strong recommendation from the pain management CPG

Providing comfortable measures are recommended to help reduce pain during bathing or showering.



Dressing

- ▶ If you find it difficult to use your hands to get dressed or put on shoes, there are a wide variety of tools that are available to help.
- ▶ Clothing materials must be very soft (cotton, rayon, and silk) and ideally with no buttons or seams.
- ▶ Protective dressings can be placed under clothing.
- ▶ Avoid warm clothing or clothes that fit too tightly.
- ▶ Seamless clothing, socks, and underwear can be used to limit rubbing on the skin.
- ▶ *Glidewear* ultra-low-friction fabric is used for clothing, blankets, pillow covers, and other accessories for people living with EB.
- ▶ Double-layer socks use two-layer fabric that protects the skin by gliding smoothly against itself and absorbing friction that can damage the skin.
- ▶ *Kickee Pants* and *Kaysie's Clothing* are other sources of clothing made with extra soft materials for people living with EB.

Personal hygiene and grooming

Special tools can improve independence in grooming tasks. Examples are long-handled hair brushes, a hair brush strap, tooth paste dispensers, long-handled sponges, and nail brushes.



Geanyne Ferreira Stüpp, living with recessive dystrophic EB, aged 21, Brazil (photo credit: Suelen Szymanski)



“ Health wise my best time in life was probably aged 20-35. I think as you get older you learn to adapt and live with your condition more. You know your limitations. I love playing golf but I know I can’t walk 9 holes let alone 18 so I always make sure a golf buggy is available when I play and I always protect my hands as much as I can. I know my skin is worse in winter, it cracks, it bleeds, and it’s very painful but I make sure I try to keep as warm and wrapped up as much as possible and apply plenty of moisturiser. ”

Mark Bristow, living with Kindler EB, aged 39, United Kingdom

Instrumental activities of daily living (IADLs) are activities to support daily life within the home and community that often require more complex interactions than those used in self-care ADLs, such as care of others, child-rearing, care of a pet, driving, emergency responses, shopping, cooking, home management, going on holiday, and financial management.



Recommendations

- ▶ Anyone living with EB at any age is encouraged to participate in some form of regular physical activity as part of a generally healthy lifestyle.
- ▶ Work with your OT (and/or MDT) to get appropriate community support to enable you to participate in education, work, and leisure and social activities.
- ▶ Working with your OT (and/or MDT) can help determine modifications or equipment needed for greater independence in leisure activities and travel.
- ▶ If you have physical concerns that limit access to driving, you can work with your OT (and/or MDT) who can help you find a driving instructor that specialises in adaptations for driving.

What does this mean for you?

People with EB can:

- ▶ lead a physically active, healthy lifestyle
- ▶ participate in events
- ▶ go to university and work
- ▶ participate in leisure, social activities, and travel.

Examples of hand exercises

Work with your OT to determine the exercises, methods, and frequency. All hand exercises should be done daily. Length of time and repeats should be individualised to your needs.



01 Stretch the space between the thumb and the index finger



02 Stretch the wrist up



03 Stretch the spaces between the fingers

There are also exercise tools that can help you, for example a gel egg, padded handle with light resistance, and a pliable ball.

Some people with EB are at risk of losing hand function and motion due to scarring, contractures, skin tightness, and pseudosyndactyly (mitten deformities). This has a huge impact on their quality of life. An OT can work to help limit loss of hand motion and strength.

OTs can work with you at an early stage to try to maximise hand function using non-surgical methods to maintain and optimise the full movement and strength potential of hand joints.

Advice should be individualised to your needs. See what your local EB team recommends and supports.



Recommendation

Work with your OT (and/or MDT) to monitor developing hand deformities, such as finger contractures and/or if spaces close or creep together. This may involve measurements of web space/finger length, hand “range of motion” (ROM), and hand function. For preserving the finger web spaces, the treatment may involve individual finger wrapping, use of splints, silicone inserts, or silicone moulds.

Hand wrapping

- ▶ Finger wrapping may decrease web space “creep” or closing while still allowing the fingers to be free.
- ▶ Hand wrapping can be done during the day or when you are sleeping.

The images below show examples of hand wrapping.



Hand splints

- ▶ Hand splints may be used to limit loss of hand motion.
- ▶ Splints can be soft or rigid and can be custom or pre-made.
- ▶ Once you start using splints you may require regular follow-up with a specialist OT hand therapist.

The image below shows an example of a hand and wrist splint.



Check with your OT (and/or MDT) to see if splints are right for you. Splints may be difficult to use. Trying mittens or gloves to prevent web creep can be an option to discuss with your team.

The suggestions in this booklet are non-surgical strategies intended to maintain and optimise the full movement and strength potential of hand joints. If your hands have worsening web creep and/or finger contractures, your OT (and/or MDT) may refer you to a specialist in hand surgery and postsurgical rehabilitation. Recommendations on this topic are NOT addressed in this booklet; they will be addressed by the “Hand surgery and hand therapy CPG” (estimated date of publication 2020). In the meantime, it is best to work with your OT (and/or MDT) to ensure you receive the best care possible.

Fine motor skills involve several different hand and finger movements and the coordination to control these movements. Some important skills include having the abilities to grasp and pinch.



Composite full grip



Tip pinch



Lateral pinch

The development of fine motor skills follows appropriate milestones in physical, mental, behavioural, and sensory processing system development when you are a child. Sensory integration is the process by which we receive information through our senses: we process this information and are able to use it to participate in everyday activities. Many people with EB have difficulty with fine motor skills due to sores and blisters on their hands and decreased finger motion.

OTs can work with you to try to optimise the full movement and strength potential of hand joints to allow functional pinch and grasp for precision, accuracy, coordination, and performance of ADLs tasks. OTs can advise on tools for doing work and ideas for improving the ability to hold things.

OTs can help people continue to be able to perform tasks that require fine motor skills with adaptations as needed.



Stief Dirckx, born with recessive dystrophic EB, (1978-2018), Belgium

Sometimes people with EB have difficulty with feeding, eating, and/or swallowing. This can start in infancy and can sometimes continue across the lifespan. Ideally, your OT will work with a MDT including doctors, dietitians, and speech therapists to help coordinate the best feeding plan for you. In some countries, your OT will also help with managing swallowing issues.

The medical team managing your oral feeding, eating, and swallowing can vary between countries.



Recommendation

Work in partnership with your OT (and/or MDT) to obtain appropriate modified tools to improve oral intake, promoting inclusion in social interactions, and improve quality of life.

OTs are able to help:

- ▶ people learn how to chew and manage food and become more accepting of different textures and flavours
- ▶ improve mealtime experiences at home and in public. Examples are:
 - allowing extra time to chew and swallow
 - taking drinks between bites to help clear the mouth well
 - recommending types of foods that will be easier to chew
- ▶ recommend special tools, such as feeding equipment.

How your OT can help

An OT is able to:

- ▶ assess ADLs and provide advice to encourage independence
- ▶ modify equipment to facilitate IADLs
- ▶ advise on suitable equipment for the home, university, work, and leisure and social environments
- ▶ appropriately train university and work staff, and other services near your home
- ▶ monitor hand function and try to maximise independent use of the hands and fingers
- ▶ support oral intake of food.

Please contact your national DEBRA group for more information on your local EB specialist clinic.



Matija Zmazek, born with recessive dystrophic EB (1983 – 2018), Croatia

*The panel was honoured with the vibrant work of a wonderful man, Matija Zmazek who sadly passed away at the end of 2018. The involvement and contribution of Matija into the CPGs have made them a great resource that will help many more people living with EB around the world.

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.

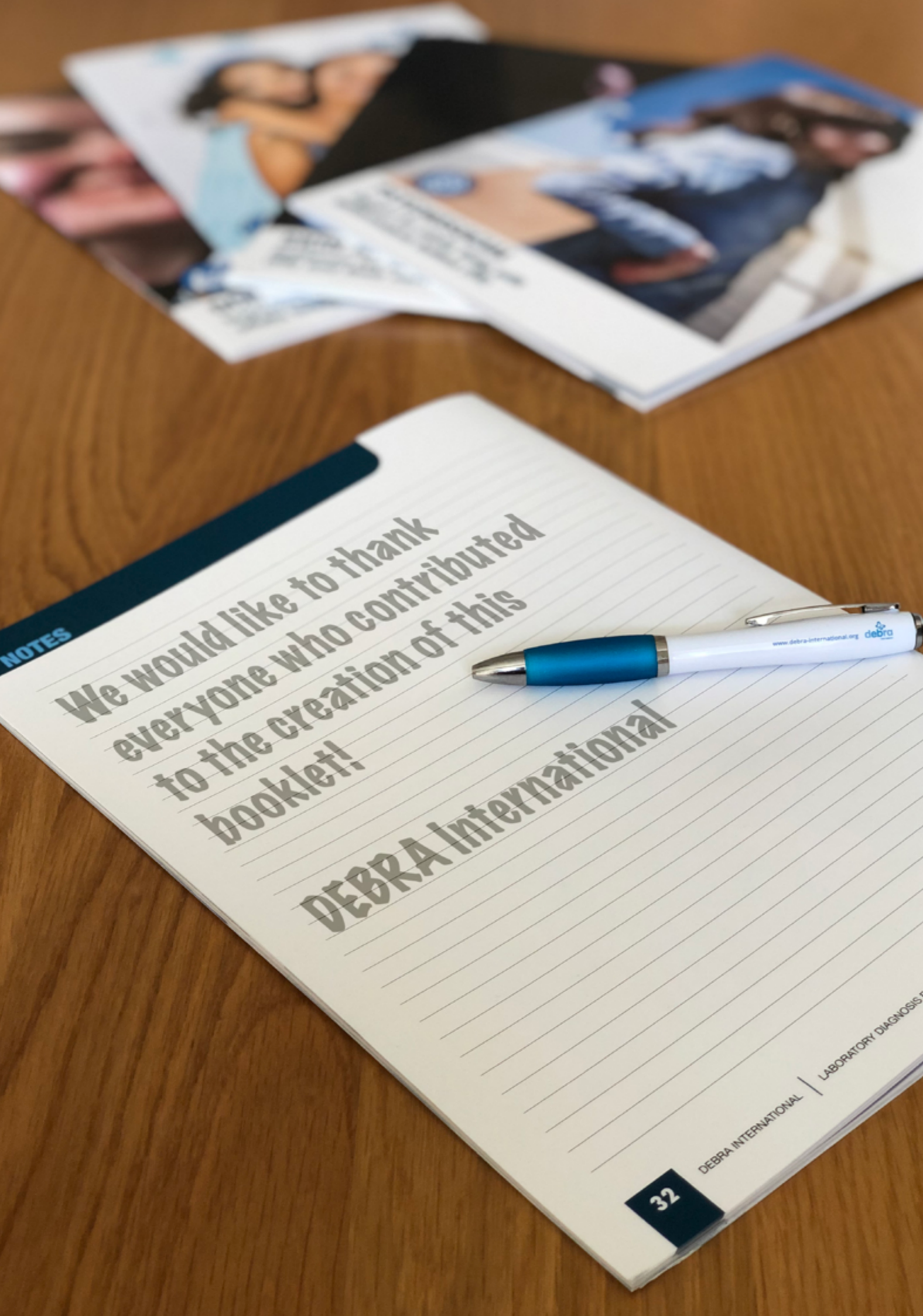
Help us create new CPGs and patient versions

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, Kattya Mayre-Chilton by email at: kattya.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





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

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 of America, 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

Occupational therapy for epidermolysis bullosa: clinical practice guidelines

This CPG was approved by DEBRA International and funded by DEBRA of America.

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



Occupational therapy booklets

Occupational therapy improving participation in daily activities for children living with epidermolysis bullosa (EB)

Other CPG topics referred to in this booklet



International Consensus Best Practice Guidelines for Skin and Wound Care in Epidermolysis Bullosa



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
- ▶ Management of Cutaneous Squamous Cell Carcinoma in Patients with Epidermolysis Bullosa: Best Clinical Practice Guidelines
- ▶ Oral Health Care for Patients with Epidermolysis Bullosa - Best Clinical Practice Guidelines
- ▶ Psychosocial recommendations for the care of children and adults with epidermolysis bullosa and their family: evidence based 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 Occupational therapy guideline produced?

- ▶ The CPG development group consisted of EB experts: occupational therapists, hand therapists, a physiotherapist, a paediatric dermatologist, a community social support lead, 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 occupational therapy 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 occupational therapy research together with the personal experiences of the panel members.
- ▶ To identify publications, eight electronic search engines were accessed, including Medline (PubMed MeSH), Embase Emtree PsychInfo, CINHALL, Scopus, and the main search engine for the National Institute for Health and Care Excellence (NICE). Searches were performed using the terms "EB and occupational therapy" and "EB and 25 interventions" with the search period ending December 2018.
- ▶ Out of 70 papers appraised, 20 were chosen for the final recommendations by nine panel members according to the Critical Appraisal Skills Programme (CASP) and Scottish Intercollegiate Guidelines Network (SIGN) quality rating.

Panel group

- ▶ J M Chan - CPG Lead (United States)
Specialist OT - Lucile Packard Children's Hospital, Stanford
- ▶ A Weisman - CPG Co-lead (United States)
Specialist physiotherapist - Lucile Packard Children's Hospital, Stanford
- ▶ A King - CPG Member (United States)
Specialist OT - Phoenix Children's Hospital
- ▶ S Maksomski - CPG Member (United States)
Specialist OT - Brooklyn Methodist Hospital
- ▶ C Shotwell - CPG Member (United States)
Specialist OT - Cincinnati Children's Hospital Medical Centre
- ▶ C Bailie - CPG Member (Australia)
Specialist OT - Sydney Children's Hospital
- ▶ H Weaver - CPG Member (United Kingdom)
Community Project Lead - DEBRA UK
- ▶ R Bodan - CPG Member (United States)
Person living with EB - California State University
- ▶ E Guerrero - CPG Member (Spain)
Social worker - DEBRA Spain
- ▶ M Zmazek - CPG Member (Croatia)
Person living with EB - DEBRA Croatia
- ▶ Dr P Khuu - CPG Member (United States)
Dermatologist specialised in EB - Lucile Packard Children's Hospital, Stanford

External review group

- ▶ B Faitli (United Kingdom)
Mother of a person living with EB
- ▶ V Zmazek (Croatia)
Mother of Matija born with RDEB (1983-2018)
- ▶ A C Rocha (Brazil)
Person living with EB

DEBRA International project team

- ▶ K Mayre-Chilton - CPG patient version project lead (United Kingdom)
CPG Coordinator - DEBRA International
- ▶ O Mullins - Editorial and format lead (United Kingdom)
Business Manager - DEBRA International
- ▶ L A Taguchi - Branding and design lead (Brazil)
Mother of a person born with EB; Marketing Director - DEBRA Brazil
- ▶ M Cardoza - Graphic designer (United Kingdom)
- ▶ A Winter - Design assistant (United Kingdom)
Fundraising Events Coordinator - DEBRA UK

-  ▶ **Argentina**
www.debraargentina.org
info@debraargentina.org
+54 (011) 3965 4298
-  ▶ **Australia**
www.debra.org.au
admin@debra.org.au
+61 (0) 427 937 003
-  ▶ **Austria**
www.debra-austria.org
office@debra-austria.org
+43 1 876 40 30
-  ▶ **Belgium**
www.debra-belgium.org
info@debra-belgium.org
+32 (0) 4 267 54 86
-  ▶ **Bosnia & Herzegovina**
www.debra.ba
djeca.leptiri@hotmail.com
+387 33 328 284
-  ▶ **Brazil**
www.debrabrasil.com.br
web@debrabrasil.com.br
+55 (047) 3237 6243
-  ▶ **Bulgaria**
www.debrabg.net
contact@debrabg.net
+359 (0) 882 919 167
-  ▶ **Canada**
www.debracanada.org
debra@debracanada.org
+1 800 313 3012
-  ▶ **Chile**
www.debrachile.cl
info@debrachile.cl
+56 2 22 28 67 25
-  ▶ **China**
www.debra.org.cn
debra_china@163.com
+86 139 1850 3042
-  ▶ **Colombia**
www.debracolombia.org
info@debracolombia.org
+57 1 62 365 09
-  ▶ **Costa Rica**
www.debracr.org
info@debracr.org
+506 2244 3318
-  ▶ **Croatia**
www.debra.hr
info@debra-croatia.com
+385 1 4555 200
-  ▶ **Cuba**
debra_cuba@yahoo.com
-  ▶ **Czech Republic**
www.debra-cz.org
info@debra-cz.org
+420 532 234 318
-  ▶ **Finland**
www.allergia.fi/suomen-eb-yhdistys-ry
suomenebyhdistys.debrafinland@gmail.com
+358 9 473351
-  ▶ **France**
www.debra.fr
contact@debra.fr
+33 (0)7 78 95 83 44
-  ▶ **Germany**
www.ieb-debra.de
ieb@ieb-debra.de
+49 (0) 6461 9260887
-  ▶ **Hungary**
www.debra.hu
posta@debra.hu
+36 1 266 0465
-  ▶ **Ireland**
www.debraireland.org
info@debraireland.org
+353 1 412 6924
-  ▶ **Italy**
www.debraitalia.com
info@debraitalia.com
+39 02 3984 3633
-  ▶ **Italy (Südtirol - Alto Adige)**
www.debra.it
info@debra.it
+39 335 10 30 23 5

-  ▶ **Japan**
www.debra-japan.com
info@debra.sakura.ne.jp
+81 (0) 11 726 5170
-  ▶ **Malaysia**
www.debramalaysia.blogspot.com
debramalaysia@gmail.com
+60 12 391 3328
-  ▶ **Mexico**
www.debra.org.mx
debramexico@gmail.com
+81 8008 0352
-  ▶ **Netherlands**
www.debra.nl
voorzitter@debra.nl
+31 030 6569635
-  ▶ **New Zealand**
www.debra.org.nz
debra@debra.org.nz
+64 04 389 7316
-  ▶ **Norway**
www.debra.no
-  ▶ **Poland**
www.debra-kd.pl
sekretariat@debra-kd.pl
+48 501 239 031
-  ▶ **Romania**
www.minidebra.ro
contact@minidebra.ro
+40 0763 141 326
-  ▶ **Russia**
www.deti-bela.ru
info@deti-bela.ru
+7 (495) 410 48 88
-  ▶ **Serbia**
www.debra.org.rs
office@debra.org.rs
+381 (0)64 308 6620
-  ▶ **Singapore**
www.debrasingapore.com
debrasingapore@gmail.com
+65 9237 5823
-  ▶ **Slovakia**
www.debra-slovakia.org
debra.slovakia@gmail.com
+421 940 566 667
-  ▶ **Slovenia**
www.debra-slovenia.si
info@debra-slovenia.si
+386 31 348 303
-  ▶ **Spain**
www.debra.es
info@debra.es
+34 952 816 434
-  ▶ **Sweden**
www.ebforeningen.se
malin.ch.net@gmail.com
+46 (0)703 146 048
-  ▶ **Switzerland**
www.schmetterlingskinder.ch
debra@schmetterlingskinder.ch
+41 62 534 16 90
-  ▶ **Taiwan**
www.eb.org.tw
taiwaneb2010@gmail.com
+886 03 5734493
+886 0966 521836
-  ▶ **Ukraine**
www.debra-ukraine.org
info@debra-ukraine.org
svitdebra@gmail.com
+380 50 331 94 97
-  ▶ **United Kingdom (UK)**
www.debra.org.uk
debra@debra.org.uk
+44 (0)1344 771 961
-  ▶ **United States of America (USA)**
www.debra.org
staff@debra.org
+1 (212) 868 1573
+1 (855) CURE-4-EB

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