

HEALTHY BODY AND SKIN

EPIDERMOLYSIS BULLOSA INFOGRAPHICS



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



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GENERAL INFORMATION

WHY ARE THE INFOGRAPHICS IMPORTANT?

The EB infographics contain information on different areas of EB clinical and social care. They are mainly picture rather than text based and target people affected by EB in low resource areas.

The idea to develop EB infographics came from the DEBRA International EB Without Borders team. The team's mission is to help people living with EB, their families, and doctors in countries where there is no DEBRA group to support them and little knowledge of EB clinical and social care.

WHO ARE THE EB INFOGRAPHICS FOR?

The EB infographics are for individuals living with or caring for someone with any type of EB. Although the EB infographics are targeted at people in low resource areas, the information is relevant to anyone living with or caring for someone with EB.

WHERE DOES THE INFORMATION IN THIS BOOKLET COME FROM?

The information in this booklet comes from the "INTERNATIONAL CONSENSUS Best Practice Guidelines Skin and wound care in EPIDERMOLYSIS BULLOSA", "Management of cutaneous squamous cell carcinoma in patients with epidermolysis bullosa: best clinical practice guidelines" and the "Foot care in Epidermolysis bullosa: Evidence-based Guideline", and from expert opinion. The information and recommendations in the guidelines come from a variety of sources including clinical research and expert opinion.

The guidelines provide recommendations for clinical care. They are based on evidence gained from medical science and, when no evidence exists, on expert opinion.

HOW TO USE THIS INFORMATION

We strongly recommend that you consult with your doctor or EB healthcare professional before using the EB infographics so that they can discuss the information with you.

DISCLAIMER

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more info: www.debra-international.org **EB Without Borders:** ebwb@debra-international.org

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Wet your hands and apply enough soap



Rub your palms together



Rub the back of each hand



Rub both hands while interlocking the fingers



Rub the backs of your fingers



Rub the tips of your fingers

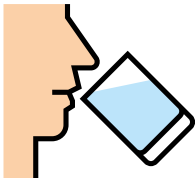


Rub your thumbs and the ends of your wrists



Rinse both hands with clean water

WASH HANDS BEFORE



Drinking



Eating



Breastfeeding



Cooking



Giving baths

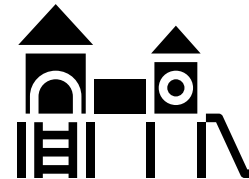


Wound care

WASH HANDS AFTER



Using the toilet



Outside play

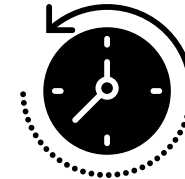


Arriving home



Touching pets

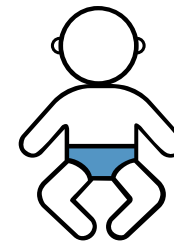
DURING DRESSING CHANGES WASH HANDS



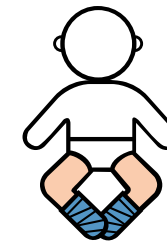
Before starting the process



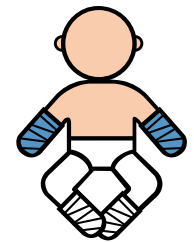
After removing clothes and bandages



After cleaning the nappy/diaper area



After cleaning and dressing lower area (feet and legs)



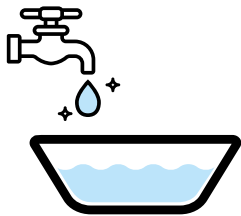
After cleaning and dressing upper area (arms, torso, and head)

more info: www.debra-international.org **EB Without Borders:** ebwb@debra-international.org

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CLEAN WATER SAFE FOR BATHING

Make sure the water is clean and safe for bathing. If you do not have access to clean water, follow our instructions on how to make your water safe.



Clean tap water



Clean water from shower head

CLEAN WATER SAFE FOR DRINKING

Make sure the water is clean and safe for drinking. If you do not have access to clean water, follow our instructions on how to make your water safe.



Bottled water



Filtered water



Boiled water

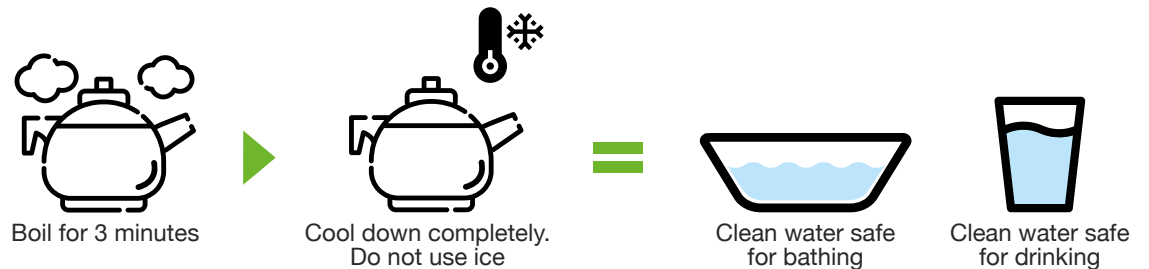
DO NOT USE UNSAFE WATER

Do not use water from rivers, lakes, or other sources even if it looks clean



IF YOU DO NOT HAVE CLEAN WATER

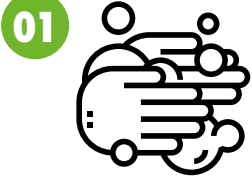
Bring the water to a rolling boil for 3 minutes and cool down before drinking and bathing



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SALT BATH - HELP REDUCE THE PAIN



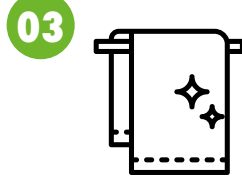
01 WASH HANDS

Follow instructions on page 2



02 BATH TIME

15 to 20 minutes



03 DRY TOWEL

Pat dry with a clean towel

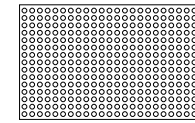
04



POP THE BLISTERS

Follow instructions on page 6 or 7

05



WOUND CARE

Follow instructions on page 6 or 7

06



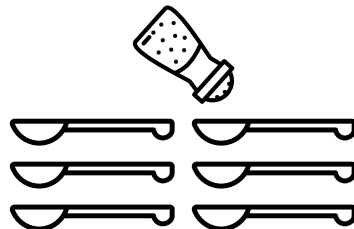
MOISTURISER CREAM/OIL

Apply to the skin to help reduce itching. Do not apply on open wounds

BATH TIME



Add 15 litres of clean lukewarm water



Add 6 tablespoons of salt (135 g)



Mix well



Check temperature (lukewarm)



15 to 20 minutes. Bandages are easier to remove during bath time

TIPS

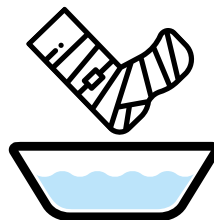


Mark bath tub with marker for accuracy and to save time



Mark cup with marker for accuracy and to save time

IMPORTANT!



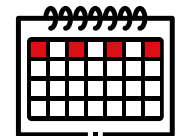
Bandages are easier to remove in the bath



Line clean towel(s) at bottom and sides of tub to avoid slipping when sitting in the bath



Pour the water on sponge to avoid direct contact with the skin

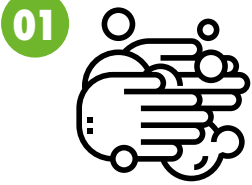


Bathing can be daily or every other day

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BLEACH BATH - HELP PREVENT SKIN INFECTIONS



01
WASH HANDS
Follow instructions on page 2



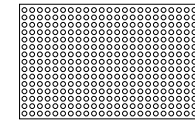
02
BATH TIME
10 to 15 minutes



03
DRY TOWEL
Pat dry with a clean towel



04
POP THE BLISTERS
Follow instructions on page 6 or 7



05
WOUND CARE
Follow instructions on page 6 or 7

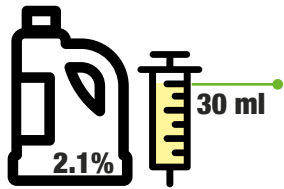


06
MOISTURISER CREAM/OIL
Apply to the skin to help reduce itching. Do not apply on open wounds

BATH TIME



Add 15 litres of clean lukewarm water



Add 30 ml of regular bleach (2.1%). To measure, use a single use disposable syringe



Mix well



Check temperature (lukewarm)

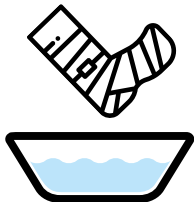


10 to 15 minutes. Bandages are easier to remove during bath time

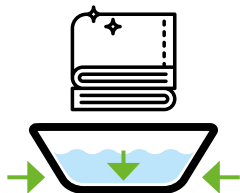


Rinse skin with clean water after bath to prevent itching and irritation

! IMPORTANT!



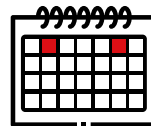
Bandages are easier to remove in the bath



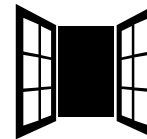
Line clean towel(s) at bottom and sides of tub to avoid slipping when sitting in the bath



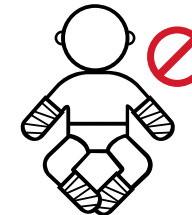
Pour the water on sponge to avoid direct contact with the skin



Bath 2 times a week (maximum)



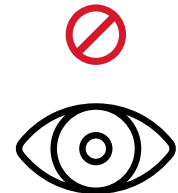
Make sure the room is well ventilated



Do not give bleach baths to babies under 1 year old



Do not drink! Keep away from children!



Avoid contact with eyes!

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WOUND CARE - SUPERFICIAL WOUNDS



01

REMOVE DRESSINGS

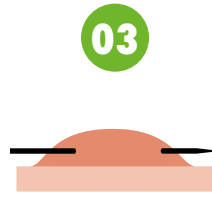
Remove clothes, bandages, and dressings very slowly



02

BATH TIME

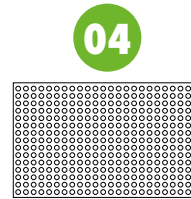
Follow instructions on page 4 or 5



03

POP THE BLISTERS

Find, puncture, and drain blisters. Instructions below



04

BANDAGE FIRST LAYER

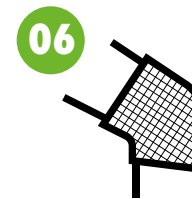
Use non-adherent dressings to protect and keep wounds moist



05

MOISTURISER CREAM/OIL

Apply to the skin to help reduce itching. Do not apply on open wounds



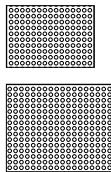
06

BANDAGE NETTING

Use bandage netting to hold the dressings in place. Do not use tape!

POP THE BLISTERS

Bigger blisters = bigger wounds! Pop a blister as soon as you see it. Cleaning and removing debris/dead tissue helps to reduce bacteria in wounds and promote wound healing



Prepare all dressing material in suitable sizes and amounts in advance to keep dressing changing times shorter

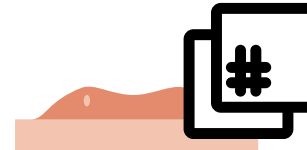
SYRINGE NEEDLE



BLISTER

SKIN SURFACE

Use a clean needle to create an entry and exit hole so the fluid can escape



Roll a soft clean cloth over the blister to expel fluid

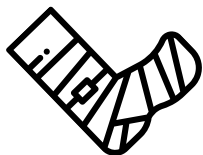


The roof should be left on the blister to protect the wound

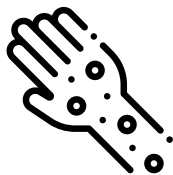


Remove dead skin around the open wound

! IMPORTANT!



Use protective bandages in areas of constant friction



Some people from very hot countries prefer not to use bandages



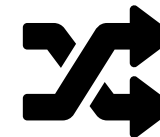
Corn starch can be used for the feet to help dry out blisters and reduce friction. Do not use on the nappy/diaper area



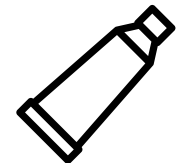
Wash scissors with soap and water, and rub an alcohol-based product on the surface. Utensils are for individual use only



Scissors with no pointy ends can be used to create an entry and exit hole instead of a syringe needle



In cases of extreme circumstances, such as war or natural disasters, follow options on pages 11 and 12.



Antimicrobial cream can be used if the wound is infected. Always consult with your doctor first

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WOUND CARE - MEDIUM-HIGH EXUDATE

01



REMOVE DRESSINGS

Remove clothes, bandages, and dressings very slowly

02



BATH TIME

Follow instructions on page 4 or 5

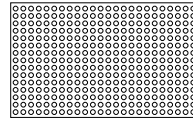
03



POP THE BLISTERS

Find, puncture, and drain blisters. Instructions below

04



BANDAGE FIRST LAYER

Use non-adherent dressings to protect and keep wounds moist

05



BANDAGE SECOND LAYER

Absorbent dressings soak up wound fluid, and offer padding and protection

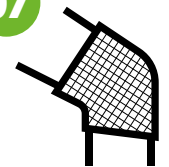
06



MOISTURISER CREAM/OIL

Apply to the skin to help reduce itching. Do not apply on open wounds

07

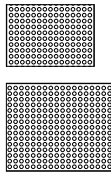


BANDAGE NETTING

Use bandage netting to hold the dressings in place. Do not use tape!

POP THE BLISTERS

Bigger blisters = bigger wounds! Pop a blister as soon as you see it. Cleaning and removing debris/dead tissue helps to reduce bacteria in wounds and promote wound healing



Prepare all dressing material in suitable sizes and amounts in advance to keep dressing changing times shorter

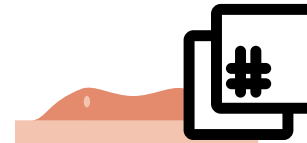
SYRINGE NEEDLE



Use a clean needle to create an entry and exit hole so the fluid can escape

BLISTER

SKIN SURFACE



Roll a soft clean cloth over the blister to expel fluid

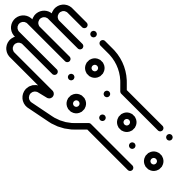


The roof should be left on the blister to protect the wound



Remove dead skin around the open wound

! IMPORTANT!



Some people from very hot countries prefer not to use bandages



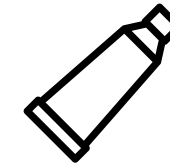
Wash scissors with soap and water, and rub an alcohol-based product on the surface. Utensils are for individual use only



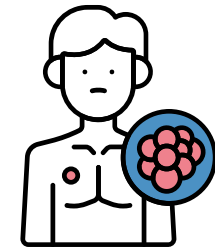
Scissors with no pointy ends can be used to create an entry and exit hole instead of a syringe needle



In cases of extreme circumstances, such as war or natural disasters, follow options on pages 11 and 12.



Antimicrobial cream can be used if the wound is infected. Always consult with your doctor first



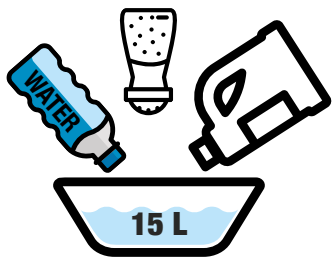
There is a high risk of developing SCC for people with severe recessive dystrophic EB (severe RDEB). Check page 9 for signs of SCC

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WOUND CARE - INFECTED WOUNDS

01



BATH TIME

Mix 15 litres of lukewarm water with bleach 2.1% (30 ml) and salt (135 g) and bathe daily until the wound infection is under control

02



POP THE BLISTERS

Follow instructions on page 6 or 7

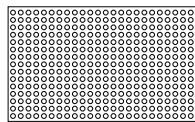
03



ANTIMICROBIAL CREAM

Apply antimicrobial cream on infected wounds

04



BANDAGE FIRST LAYER

Use non-adherent dressings to protect and keep wounds moist

05



BANDAGE SECOND LAYER

Absorbent dressings soak up wound fluid, and offer padding and protection

06



MOISTURISER CREAM/OIL

Apply to the skin to help reduce itching. Do not apply on open wounds

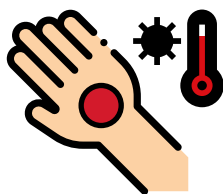
07



BANDAGE NETTING

Use bandage netting to hold the dressings in place. Do not use tape!

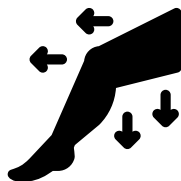
SIGNS OF SKIN INFECTION



Redness and heat



Increased fluid



Swelling



Odour



Non-healing wounds or wound breakdown



Increased pain



Fever

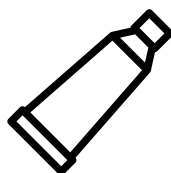


Dizziness

DOCTOR PRESCRIPTION



See the doctor if signs of infection persist for more than 3-4 days



Antimicrobial cream can be used if a wound is infected. Always consult with your doctor first



Pain control



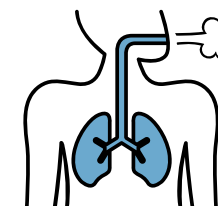
Monitor

! IMPORTANT!

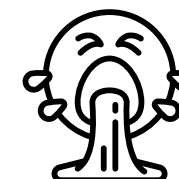
See the doctor if you have the following symptoms:



Fast heart rate



Fast breathing



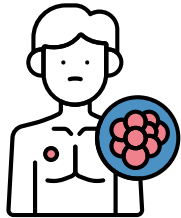
Nausea/vomiting

more info: www.debra-international.org EB Without Borders: ebwb@debra-international.org

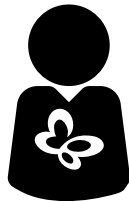
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SIGNS OF SQUAMOUS CELL CARCINOMA (SCC)

There is a high risk of developing SCC (skin cancer) for people with severe recessive dystrophic EB (severe RDEB). For other groups (dominant dystrophic EB, intermediate RDEB, RDEB inversa, pretibial dystrophic EB, EB pruriginosa, intermediate junctional EB, and Kindler EB), the risk is not so high and it does not usually occur as early. Clinical screening for these lower-risk groups should usually start from age 20 years and take place every 6–12 months.



There is a high risk of developing SCC for people with severe RDEB



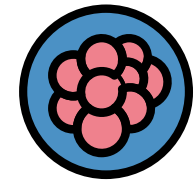
People with severe RDEB should have a full skin examination every 3–6 months from age 10 years



Areas of skin clinically suspicious for SCC should be biopsied for histological evaluation



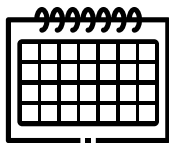
Clinical screening should be undertaken by a dermatologist and/or specialist nurse with experience of EB wounds where possible



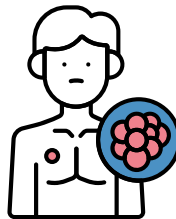
If an SCC is diagnosed, 3-monthly screenings should be undertaken subsequently

SIGNS OF SQUAMOUS CELL CARCINOMA (SCC)

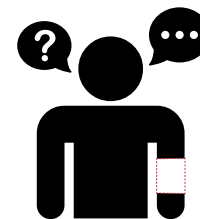
People with severe RDEB should see the doctor regularly to check for signs of skin cancer.



A nonhealing wound, lasting longer than normal EB wounds (e.g. 4 weeks or more)



A rapidly growing wound, especially one that is heaped up, resembling exuberant granulation tissue



A wound with altered sensation relative to normal EB wounds (e.g. tingling or increased pain)

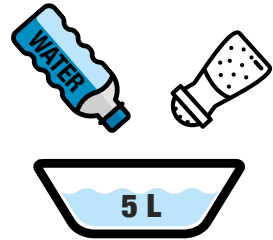


Increased pain

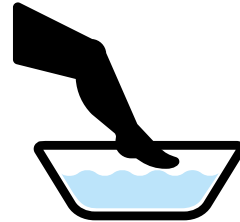
more info: www.debra-international.org **EB Without Borders:** ebwb@debra-international.org

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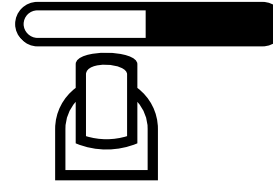
NAIL CARE FOR TOES AND FINGERS



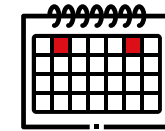
Add 5 litres of clean lukewarm water and 2 tablespoons of salt (45 g)



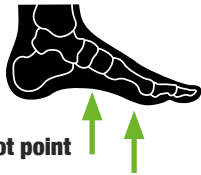
Soften the nails by soaking them in lukewarm water with salt



File nail surfaces with an emery board and keep nails trimmed straight across



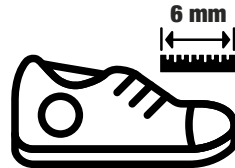
For adults and thick nails = daily
For children = once per week



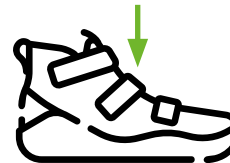
pivot point

metatarsal heads

The pivot point of the balls of the feet and metatarsal heads are where blistering tends to be most prevalent



There must be a minimum of 6 mm in front of the longest toe



Styles with a lace, touch and close fastening, or buckle provide most adjustment



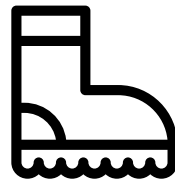
The heel must not slip up and down at the back



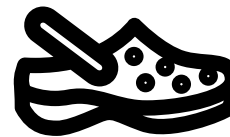
Ideally the tread pattern should extend over the whole sole and heel area



There should be enough width in the shoe to accommodate the whole foot; there should be no pressure points



Shoes with sheep skin inside can offer cushioning. Be aware of overheating



For summer choose shoes that let the feet breathe



Healthcare professionals and people with EB have reported the benefit of using corn starch on the soles of the feet and in between the toes to help control excessive moisture and reduce friction

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WOUND CARE - EXTREME CIRCUMSTANCES

IMPORTANT! The following unorthodox wound care options should only be used in the cases of exceptional or extreme circumstances, such as war or natural disasters. For all other situations, please follow the products used in the Skin and Wound Care guidelines

BANDAGE DRESSING = **CLING FILM** → Put on open wounds or intact skin. Do not put it on too tight

Keeps the wound clean and moist, which helps with the pain

Apply antimicrobial cream. Always consult with your doctor first

Use padding between two layers of film for protection

Be aware of potential overheating

Change daily to prevent adherence

BANDAGE DRESSING = **CIGARETTE PAPERS** → Put on open wounds

Allow to float off if bathing or use water to remove

Change daily to prevent adherence

MOISTURISER CREAM/OIL

BANDAGE DRESSING = **BANANA LEAVES** → Clean the banana leaves with hot water

Smear the liquid paraffin/Vaseline on to the leaf before using it

Can be used as a mat to lay a baby on if there are more wounds on their back

Olive oil is known to have anti-inflammatory properties

Coconut oil

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WOUND CARE - EXTREME CIRCUMSTANCES

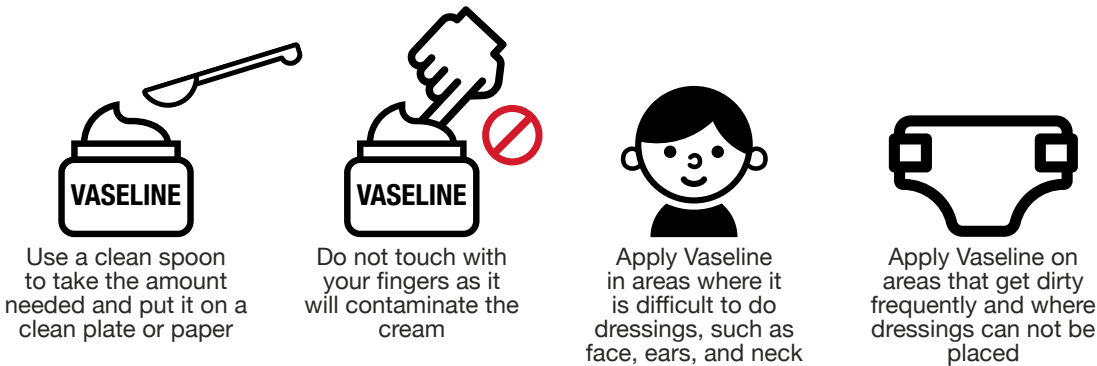
! IMPORTANT!

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VASELINE AND LIQUID PARAFFIN

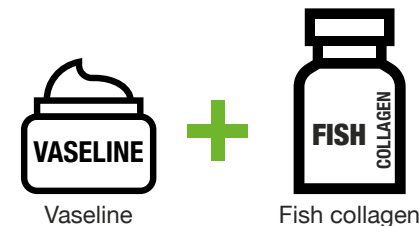
Vaseline is classed as a barrier product so it will also help prevent friction. It is an ointment and greasy so it will also keep wounds moist, which is needed to aid wounds to heal.



VASELINE & COLLAGEN

Some healthcare professionals with experience working with people with EB in India have noticed a benefit of mixing Vaseline with collagen particles that are obtained from fish collagen.

The paste mix can be applied to wounds directly. It will form a thin film to help the wound heal well.



TIPS

If you are unable to get an alcohol-based product to clean scissors, follow the method below:



Boil scissors for 15 minutes if you want to reuse them. For individual use only

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ICON KEY



Consult with your doctor or EB healthcare professional before using the EB infographics



Do not face the shower head directly towards the skin as this can be painful



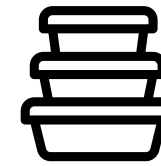
Do not stay in the bath for longer than instructed. Cells can take up water and later leak out making dressings wet. Salt baths help to avoid this



If you do not have a bath, you can use a blow-up swimming pool. It must be cleaned well after use



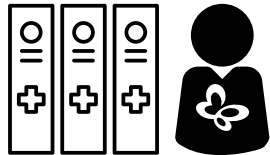
If you do not have a bath, soak clean gauze in bath mixture and put on the wounds for at least 15 minutes. Do not allow the gauze to dry out. See pages 4 and 5 for bath mixture options



Keep unused dressings in a clean container until used



This icon has important information on what you should not do



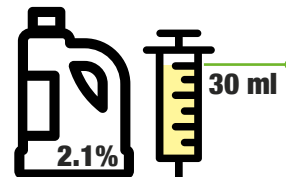
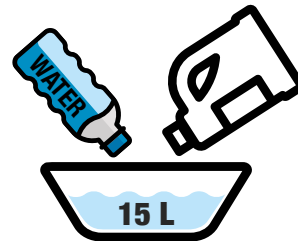
Read the Clinical Practice Guidelines (CPGs)/ Patient Versions for more information



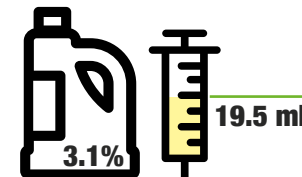
Tablespoon sizes can vary. One tablespoon = 22.5 g (salt)

BLEACH VARIATIONS

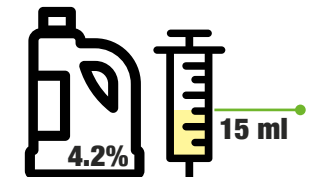
Mix 15 litres of lukewarm water with bleach. Follow instructions below for the amount of bleach for each strength. To measure, use a single use disposable syringe. If reusing, label and store away from the reach of children.



For 2.1% add 2 ml for every litre of water. 15 L = 30 ml



For 3.1% add 1.3 ml for every litre of water. 15 L = 19.5 ml



For 4.2% add 1 ml for every litre of water. 15 L = 15 ml

OTHER EB INFOGRAPHIC BOOKLETS

EB requires a multidisciplinary team for the care of EB. Wound treatment alone is not effective as we also need to learn about a healthy diet and other topics. Check the other infographics that we have created to help you manage life with EB.



Balanced life and social life



Care of a newborn



Healthy body and skin



Healthy eating and nutrition



Healthy mind and control



Pregnancy and birth



Stay active and mobile



What is EB?

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DEBRA INTERNATIONAL

DEBRA International is the umbrella organisation for a worldwide network of national groups that work on behalf of those affected by the rare genetic skin blistering condition, epidermolysis bullosa (EB). The first DEBRA group was created over 40 years ago; there are now groups present in over 50 countries around the world.

www.debra-international.org
office@debra-international.org

EB WITHOUT BORDERS

EB Without Borders is a key initiative of DEBRA International. Its mission is to help patients, families, and doctors in countries where there is no DEBRA structure to support them, and to assist new groups to form and develop.

ebwb@debra-international.org

EB INFOGRAPHICS SURVEY

Help DEBRA International evaluate how the EB infographics are helping you. Complete the survey to give your opinions and suggestions.

<https://surveyhero.com/c/EBinfographics>



DEBRA International Congress in New Zealand (2017) Photo credits: ©Silver Duck

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Get involved with **DEBRA International**

THE WORLD'S LEADING EB PATIENT ADVOCACY AND SUPPORT NETWORK

DEBRA INTERNATIONAL IS REGISTERED AS A CHARITY IN AUSTRIA (ZVR 932762489)



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