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EB CARE TIPS: Daily Living for Epidermolysis Bullosa (EB)

debra of America has compiled a list of options that may be useful for various activities of daily living for those with Epidermolysis Bullosa (EB).

The following collection has been compiled from several sources, including suggestions from community members with different forms of EB. Because a suggestion may not pertain to every individual, and there is no one product that works for everyone, discretion and experimentation will guide you and your physician in choosing the methods and products that best apply. It is important to note that this is just a small list of the various EB-friendly products that may be useful to a person.

Adaptive Equipment

- **Heelbows:** These are thick polyurethane pad helps protect elbow or heel. Plush terry loop material is soft on the skin.
- **Homcraft Long-Handled Combs and Brush:** Ideal for shoulder weakness or limited range of motion. Fold for compact storage.
- **Lock Laces:** Lock Laces allow the user to simply slip shoes on and off.
- **Door Knob Extender:** Extension handle converts a doorknob into a door lever providing extra leverage for people with limited hand function.
- **Multi-Purpose Power Grip:** Designed for individuals with limited hand or finger strength, this lightweight, handy helper concentrates the power of the entire hand onto its slip-resistant jaws. Opens bottles, jars, doors, childproof medicine bottles; pulls up socks; lifts pans; holds nails; pulls plugs out of electrical sockets, etc.
- **Nosey Cups:** Cup is notched to allow room for the nose and eyeglasses when cup is tipped.
- **Clip-On Food Guard:** Prevents food from spilling over the edge of the plate.

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- **U-Bend It Utensils:** Designed with a twist in the shaft that allows utensil to be easily hand bent to either side at any angle. For people with upper extremity weakness or reduced range of motion.
- **Foam Tubing:** Use to build up tool and utensil handles.

Bathing Options

Lining Options - Examples include:

- Antibacterial Microfiber Enviro Cleaning Cloths - Contains EPA Registered Killing Power SilverClear™ Treatment eCloth
- The Shammy
- Yoga Mats

Bathing Systems - Examples include:

- Rifton Blue Wave: Bath and Shower Chairs that are portable, height-adjustable bathing systems for people with special needs. Learn more here.

Learn more about bathing with EB at debra.org/how/prepare-bath

Diapers

Cloth and disposable diapers have both been used by parents with EB babies. When using cloth diapers, consider investing in wicking diapers, as opposed to traditional cotton diapers that stay wet against the newborn's skin. Examples include:

- **Thirsties Duo Wrap Snap:** Size 1: 6-18lbs; size 2: 18-40lbs. They have an outlet that sells slightly imperfect products at reduced cost. Learn more here.
- **Happy Heiny's One Size Cloth Diapers:** Comes with a newborn and medium/large insert (Helpful hint from the manufacturer: Should the fleece roll out? Yes, it should roll out. Do not try to roll the fleece in.)
- **FuzziBunz One Size Cloth Diaper:** 7-30lbs from Nurtured Families, this diaper is a quick dry fleece. Baby feels dryer faster and fleece stays nicer longer.

- **Sugar Peas Diapers:** Size 1: 6-20lbs; Size 2: 18-38lbs. Made entirely of organic hemp fleece.

Using disposables is sometimes possible, either on their own or inside a microfiber diaper cover if the diaper insert cannot absorb enough. Options include: Pampers Swaddlers, Huggies Supremes, Huggies Ultratrims, and Walmart White Cloud.

Driving Options

- **Padded Steering Wheel Covers:** Examples include Zento Deals soft stretchable sheepskin steering wheel cover, and Auto Drive Neoprene Steering wheel cover.
- **Seatbelt Covers:** Examples include Zento Deals soft faux sheepskin seat belt black shoulder pads, and Bell Automotive Black Memory Foam Seat Belt Pad.
- **Key Turner**

Scooter Options

- **Scooters Travelscoot:** The lightest and most compact electric mobility scooter.

Shoe Suggestions

Adults & Kids

- **Adidas Climacool:** Athletic shoes with ventilation.
- **Nike Flyease:** Sneakers that zip open around the back and close with Velcro (but looks like a lace-up shoe).
- **Overland:** Sheepskin slippers and shoes.
- **Pedors:** Specializes in orthopedic footwear that stretches to accommodate many types of forefoot problems as well as other issues related to the health of the foot.
- **LL Bean:** Berber Fleece Slippers, Fleece Slippers with Drawcord, and Fleece Slippers with Ankle Cuff are all good options.
- **Crocs**
- **Minnetonka Moccasins**
- **Uggs**

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- **Billy Footwear:** Zipper shoes with easy FlipTop closure

Kids Only

- **PediPed:** Shoes with soft rubber sole, rounded edges that mimic the shape of a child's foot, heel stability, and a soft toe box to allow toes to grip the floor.
- **PLAE:** Shoes that follow the natural contour of a child's foot and has interchangeable tabs that adjust.
- **Robeez:** Promotes natural foot function with a soft sole design built to flex and bend.

Sock Suggestions

- **EZSOX:** Seamless socks that have loops to increase independence with dressing.
- **SmartKnitKids:** Seamless and moisture wicking socks; also make socks to wear with AFO's.

Splinting/Positioning Options

- **Comfyrene® Elbow Orthosis:** Easily adjustable for optimal fit. Simply bend the orthosis and cuffs into the desired position.
- **Comfyrene® Knee Orthosis:** This slim line knee splint is simple and easy to use. Simply “bend-to-fit”. Cuffs are also adjustable for optimal fit. Splint can be adjusted and readjusted as needed.
- **Conforming Comfort™ Thigh/Knee/Ankle Separator:** Specially designed to provide abduction for the thigh, knee and ankles while sitting. Also protects the bony prominences from the knees to the ankle, helping to reduce the risk of skin breakdown. Fluid-resistant cover.
- **Bioconcepts Custom-Sized Gloves:** Measured to fit for patient to help to preserve web spaces. Compression can be specified to be minimal (10 mmhg) or less.
- **Otoform - K/c Elastomer:** Putty-like silicone is used in conjunction with splints.
- **Gelbodies Heel & Ankle Protectors:** Soft and stretchy. The Coolband material is skin compatible, breathable and can be machine washed. Lightweight, discreet and provides protection for areas at risk from pressure sores.

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Stroller Options

- **Convoid:** Lightweight and compact folding wheelchairs. Options include:
 - Basic Cruiser CX10
 - Convoid Adult Basic Cruiser CX18
 - Convoid EZ Rider Wheelchair

Toothbrushes

Toothbrushes with ultra-soft nylon bristles (softened under warm water) and a small brush head is most often recommended. Good teeth brushing technique is also extremely important. Other devices include:

Adaptive devices for limited manual dexterity. Examples include:

- Collis Curve

Ultrasonic powered Toothbrushes. Examples include:

- Emmi-dent Toothbrush - Emmi-Dent is generously providing an additional 10% off the sale price of their emmi®-dent oral waver™ Starter Pack for children and adults with EB! Use the code "DEBRASAVE" at check-out to redeem. Email staff@debra.org for more information.

Wheelchair Options

- **Quantam Q6 Edge Power Wheelchair:** Engineered to meet the performance needs of the most active user. The Q6 Edge accepts a complete range of seating and electronics options.
- **Biodynamics Seat and Back Cushions:** Made with viscoelastic memory foam.
- **Rubber Dome Joystick Handle**

**Please note that all medical information given by debra of America is for informational purposes only. Our information is not intended to substitute the care and guidance given by a qualified physician. All regimens of care should be discussed with the patient's doctor. Always check with your physician prior to starting any medications or treatment regimens.*