

Information Leaflet for Education Staff

Recommendations for Children with EB in Schools

Occupational Therapy



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What is EB?

Epidermolysis Bullosa (EB) is a rare and severe genetic condition that causes skin blistering and can impair gross and fine motor skills.

What is Occupational Therapy and how can it help?

Occupational Therapy works with children and young people to assess their needs and ability to engage in activities of daily living; self-care, productivity (school) and leisure. We encourage independence and can advise and prescribe equipment, building adaptations or strategies to enable a person to participate in their environment effectively.

Children with EB have fragile skin which can blister and tear easily which makes everyday tasks more difficult. There is no cure and daily life involves wound care, pain management and protective bandaging. These recommendations are for education staff who have a child or young person with EB in their school and want to encourage their full participation and minimise friction to the skin.

1. Adaptations and equipment

There is no standard equipment made for children or young people with EB but there are simple modifications you can make to their school environment to prevent blistering and to promote inclusion in activities.

In the Classroom Example of Soft Chair

- A soft chair should be provided that allows the child sit at a 90° angle and has no sharp edges. Ensure there are no bars underneath the table that the child is likely to bang her/his leg off.



Example of foam piping

- A height adjustable table or chair would be preferable to allow the child to work at different levels in sitting and standing.
- The table edges should be all rounded and can be covered with sheep skin* or foam piping to reduce any friction (this can be sourced at any DIY store).



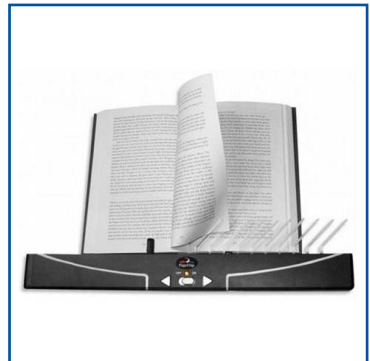
Example of stirex scissors

- Which self open and only need hand pressure to close



Example of book turner

- Ensure books are covered in foam or felt material to protect the child from sharp edges.
- A book turner can be sourced to assist reading and turning pages if necessary. Alternatively an e-book can be used if available.



Example of cutlery grippers

- If the child eats in school and requires adaptive cutlery they can be referred to their local Occupational Therapist to assess for suitable cutlery.
- If maintaining a firm grip on cutlery is an issue, simple adaptations can be tried using foam padding to make the handle larger and softer.



*The sheepskin can be purchased online from numerous different providers

In the Bathroom

- Foam/padded toilet seats can be used and sourced from your local occupational therapy service or online catalogues. Suitable companies include NRS, Amazon, Homecraft, Boots.
- The toilet space needs to be of ample size to facilitate a turning circle of a wheelchair (if applicable) at approximately 60 inches of space to make a 360-degree turn (depending on size of wheelchair).



Around School

- Depending on the child's mobility, he/she may require level access or a lift to access all rooms their peer's access.
- The door width should be approximately 32 inches (82cm) wide to allow wheelchair access if required.
- The doors need to be light weight and open both forward and backward to allow for wheelchair users to open the door going in and out of the bathroom independently.
- School bags can be heavy and difficult to carry for children with E.B. Using a bag on wheels, getting their friends to help carry books or using a bag with thick padded straps may assist

2. Activity to promote independence and inclusion

A "can do" approach is essential rather than a "can't"

A child with EB can be restricted in the activities he/she participates in due to the risk of skin blisters and this can impact them in a number of ways. Being unable to carry out the same activities as their peers can make them feel excluded, and does not give them as many opportunities to explore their environment, social interaction and for sensory experiences. They can suffer from pain and fatigue which also impacts on their ability to attend and concentrate on tasks. This can often lead to frustration and appearing to withdraw from wider school activities.

Activity Ideas;

- Set up activities that include the child. For example, in P.E. let them take the scores of the football game.
- Adapt activities to make it more suitable for the child to complete.
- Assist the child with part of the task but allow them to complete it in order to gain a sense of achievement.

- Allow the child to be at top of the line or at the back to prevent any accidents.
- It may be helpful to let the child leave class early to move to the next class to avoid any crowds and to allow them to take their time.
- Allow regular breaks for the child to promote quality of work rather than quantity and assist with pain management.
- When the child is old enough make goals, talk with them to find out what is important to them and what they want to achieve. Children with EB are experts in their own condition and will still have dreams and aspirations!
- Give them roles within the classroom to make them feel involved and valued.
- Break down activities that are difficult to achieve step by step to problem solve more effectively.

3. Fine motor activities and handwriting

Often children with EB have difficulties with their fine motor skills due to blistering, scarring and/or contractures on their hands and fingers which affects their ability to engage in school for activities like;

- Handwriting
- Arts & Crafts
- P.E.

Here are some examples of ways you can assist to improve finger dexterity and strength:

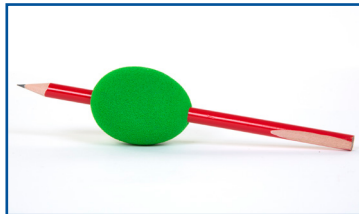
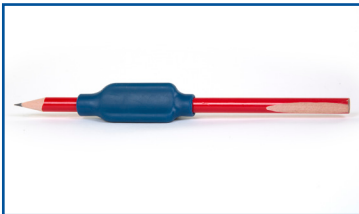
Fine motor activity ideas:

- Clay, therapy putty, play-doh, bread dough. These are all excellent materials for squeezing, squishing, pushing, pulling and moulding.

- Try hiding small objects (beads, pennies, beans) inside therapy putty or play doh and then try pulling them out.
- Use a rolling pin to flatten it out, then use cookie cutters to make shapes
- Mega Blocks are large sized Legos and are best for preschool age children
- Legos and K'nex are better for older children
- Spray bottles: help water plants or spray the windows to clean.
- Sponges: squeezing to wring out the water is great for strengthening hands and forearms.
- Pop the bubbles on a large or small bubble pack by pinching with thumb and index finger or by pushing down on bubbles when sheet is placed on a hard surface.
- Finger football – tear strips of paper with two hands and with one hand use fingers to make little balls, and then use each finger to flick the balls into goals.
- Baking is a great activity to involve the fingers and hands – scones, cupcakes, biscuits, icing tubes
- Craft activities that require using bottles to squeeze but always ensuring the skin is protected.
- Tongs, tweezers, connected chop sticks, pegs: use these to pick up small objects for sorting such as; cotton balls, marbles etc
- Push a toothpick point into a styrofoam tray or plate, or in aluminium foil placed over craft foam or corkboard to make a picture.

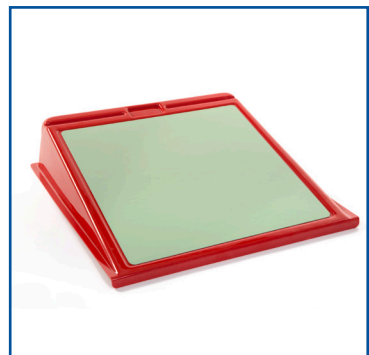
Adaptations for handwriting:

- As part of pre-writing skills, use non-pencil activities to draw/write for example; chalk, foam, magic writing boards, whiteboards, water paint with wet paint brushes on a chalk board, wall or paving outside. These can be a good alternative and reduce frustrations for the children who aren't succeeding at handwriting and are still working towards the same goal.
- Using pencil grips made of rubber or foam can decrease the friction and pressure, and be more comfortable to use while encouraging a tripod grip.
- Stabilo" pens and pencils are ergonomically designed to reduce pressure required on the grip and to encourage a more functional tripod grasp.



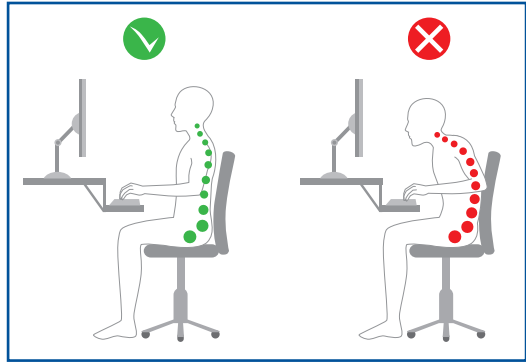
Example of Sloped Board

- Using a sloped board can create a more optimal posture for handwriting enabling better visual and fine motor skills.



Example of correct seated posture

- Ensure the child is sitting at a 90 degree angle with feet flat on the floor, on a sufficiently supportive chair at the correct desk height. Use a book or box under the feet if they are not flat on the floor.



- Using ipads and computers are another option to allow the child gain a greater sense of achievement and to keep up with their peers. These should be used alongside hand-writing which provides a key component for hand and finger strengthening and hand eye coordination skills. Some laptops can be heavy and difficult to transport and fit in their schoolbag. "Mac Air" is a make that have small and lightweight laptops but other manufactures are available also.

Useful Contacts

A very useful resource;

Occupational Therapy in Epidermolysis Bullosa, A Holistic Concept for Intervention from Infancy to Adult. By Hedwig Weiz & Florian Prinz

Further Information

If you require further assistance in Occupational Therapy refer your student to the local NHS community children's Occupational Therapist.

This booklet has been developed in collaboration with DEBRA UK



DEBRA is the national charity that supports individuals and families affected by Epidermolysis Bullosa (EB) – a painful genetic skin blistering condition which, in the worst cases, can be fatal. Visit www.debra.org.uk.

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