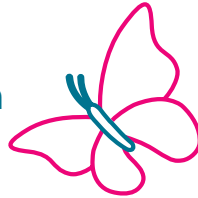


# Epidermolysis Bullosa Health and Emergency Care Plan

Attach photo  
for easier  
identification  
(optional)

## Supplementary Documentation for School Health Care Plan



Epidermolysis Bullosa (EB) is a rare genetic skin disease. People with EB are missing a gene in one of the layers of their skin that normally helps to glue their skin together effectively. People living with EB can develop blistering and wounds from friction from everyday activities. There is no cure, and preventative measures will greatly assist in reducing the development or severity of wounds.

The following plan provides guidance for preventative practice and risk management in a school environment. This plan should be used in consultation with parents, carers, EB clinical staff, and school staff.

### My Details

Name:

Date of birth:

Date of plan:

Date of review:

Authoriser of plan (e.g. Parents, EB Nurse):

Individual diagnosis:

Brief description of condition (e.g. clusters of blisters on hands):

## School

Name of School:

Principal:

Phone:

Email:

Teacher / Class:

## Emergency Contact

For all medical emergencies call 000

Parent / Carer 1:

Phone:

Parent / Carer 2:

Phone:

GP / Primary Medical Carer for EB:

Hospital Providing Specialty EB Care:

## First Aid

At school my first aid kit will be located:

Staff member in charge of my first aid kit:

Primary staff member trained to help look after me:

Specified role of school first aider after discussion with primary treating team and parents:

## Key Contact Details

Clinical Nurse:

School aide / support worker:

Other key contacts:



# Epidermolysis Bullosa Plan for School Environment

## Section 1 : Writing / drawing / typing / equipment

- No to assistance.
- Yes, to needing assistance with writing/drawing/painting or performing fine motor skill tasks in class.

If assistance is needed, check any boxes that may apply to your child on a given day:

- I occasionally need help, I may use a preventative dressing or padding to help.
- Sometimes I need to use different pens/tools than other children.
- I need to take breaks when my hands are sore, or I have blisters on my hands.
- I need extra time when my hands are sore, or I have blisters on my hands.
- I have a computer or iPad to use instead of writing.
- A person will help me with my writing.
- High school subjects such as design and technology, including cooking, sewing, science experiments, and woodwork, will need to be adapted to include padding of equipment or assistance to complete some tasks. Please add additional documentation in consultation with your teacher for this item.

## Section 2 : Food

- No to assistance.
- Yes, to needing assistance that differs from my peer's developmental abilities with eating while I am at school.

If assistance is needed, check any boxes that may apply to your child on a given day:

- I occasionally need assistance to open food packets when my hands are sore.
- I need assistance to keep wounds on my hands clean while I am eating.
- I need assistance to re-do dressings on my hands after I eat.
- I need to eat a soft diet when I have blisters on my mouth because it hurts when I chew hard food.
- It is important to communicate with my parents if I cough or gag when I eat because sometimes I need to have my oesophagus checked.
- I regularly need help with eating.
- I have a staff member allocated to help me with meal times.

### Section 3 : Toileting

- No to assistance.
- Yes, to needing assistance with toileting.

If assistance is needed, check any boxes that may apply to your child on a given day:

- The help I require is age and developmentally appropriate, and is not related to the EB diagnosis.
- I will need some help if my hands are sore or have blisters.
- I will need help with some fine motor skills such as buttons, or zippers when I have blisters on my fingers.
- Occasionally I need help to wipe my bottom.
- I will need to catheterise myself or have a trained staff member assist with catheterisation to help me pass urine. There will be separate documentation and education or training for catheterisation provided by: \_\_\_\_\_
- Other: \_\_\_\_\_

### Section 4 : Uniform

- No to assistance.
- Yes, to needing changes to my school uniform to reduce friction or the development of blisters or new wounds.

The following items of clothing will need to be discussed between parents, teachers, and the school principal to agree on options of less abrasive / softer / low friction items that will be considered acceptable as a school uniform.

- School shoes (joggers, lightweight shoes, breathable fabrics can cause less friction and assist with healing of wounds on feet).
- Socks (lightweight, natural fabrics with loose elastic around the top will assist keeping feet cool, create less friction on areas of pressure).
- Trousers (use of shorts in hotter weather will assist in keeping a child cool, reduce the development of new blisters from heat, and reduce friction behind knees).
- Dresses or shirts (adaptations to uniforms with zippers or hard buttons may assist in the reduction of friction under uniform pressure areas such as underarms or necklines and collars).
- Tie (the ability to remove a tie or not wear a tie if there are neck wounds or redness / itch appear under the tie area will reduce the impact on current wounds and reduce the chance that new blisters will develop).
- Sports uniform (adaptation to synthetic uniforms may assist in keeping a child cooler when they play sport. Preventative padding and wound care can assist under sportswear such as goggles, shin pads or gloves).
- My clinical EB nurse / team can assist with the development or support of this plan.

## Section 5 : General care / handling and mobility

- No to assistance.
- Yes, to needing assistance or changes to the care, handling or my mobility around the school.

If assistance is required, check any box that may apply to your child on a given day:

- Please consider where and how I walk around the school. If I am tripped or knocked over I may develop blistering or a large wound. This will need to be cleaned as outlined under “wound care”. Dressings and wound care. Young children with EB may benefit from walking at the front of lines with a teacher.
- I need space to sit calmly and not be surrounded by other people. Please consider where I will sit during prolonged events such as assembly or shows.
- When I have lots of wounds or blisters, I might need assistance to mobilise around the school.
- Options that will help me include the use of a:

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Or extra time allowed to get around.

## Section 6 : Weather

- No to assistance.
- Yes, to needing changes to my activities during very hot weather.

Extreme temperature days or prolonged periods of hot weather can cause the development of new blisters, and children with EB who are attending school often require consideration for activities undertaken during these times.

- I need my chair / bed to not be in direct sunlight or next to the window / heater.
- I may need access to an air-conditioned room during playtime / lunch or sport so that I can cool down.
- I would like to participate in excursions and sport, but I may need access to a ‘leave early plan’ if it is too hot.
- A flexible plan for me to have access to airconditioned rooms such as the classroom or library during hot days during recess or lunch will help. Please consider allowing friends to attend with the student to promote socialisation.

Teacher allocated to organising this:

## Section 7: Emotional Needs

The emotional care of children with a chronic disease is always important to manage and be aware of the impact on their life. Coordinated efforts between family, school, and health care workers can help to identify issues related to their emotional and mental health and address these early with appropriate support.

- I may have feelings about my blisters, scars, or dressings which may affect my emotional wellbeing and development.
- I am happy to tell others about EB.
- I would like to have some education for my classmates put in place, so I do not need to tell others about it all the time.
- I am happy for other families, parents, teachers to be told about my condition so that others can be gentler with me in the playground.
- If you are concerned about my emotional and mental health at school, please contact:  

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- School counsellors, external counsellors, or members of a speciality EB team may be able to assist with this matter.

## Section 8: Pain Management

- No to assistance.
  - Yes, to have a pain management plan in place.
- If there is a pain management plan, check any box that may apply to your child on a given day:
- I may complain I am sore.
  - I have a medication plan in my care plan stating weight, dosage, frequency of medication, and contact details.
  - My medication is located: \_\_\_\_\_
  - Method of communicating complaints of pain and use of medication to family includes:  

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  - If I still have pain after taking prescribed medication, please contact my family so that my medication can be reviewed.

## Section 9 : Wound care

- No to assistance.
- Yes, to requiring assistance with wound care and blister management while I am at school.

If assistance is required, please select all that apply to your child on any given day.

- I can lance my own blisters and apply new dressings while I am in school. I will need a safe / clean place to do this and to dispose of needles and dressing products.
- I need assistance from the person trained in helping me with blister management while I am at school. Name of staff member trained to assist me:

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- I would like you to call my parents if any wound care is required while I am at school.
- I have my own carer / staff member with me at school who can assist me with everything.
- I have a communication book that should be used for any first aid or wound care needing attention while I am at school.
- The dressings that I use on wounds if I need attention at school include (please include layer by layer list and brand name so staff can recognise them in first aid kit).

Emergency cover: \_\_\_\_\_

Contact layer: \_\_\_\_\_

Second layer (if any): \_\_\_\_\_

Padding (if any): \_\_\_\_\_

Cleaning solution (if used): \_\_\_\_\_

Wound care comments:

## Final comments by family

**This care plan has been developed and discussed with the following people.**

Parent(s):

Principal:

Class Teacher:

Aide:

## Documents attached

- DET or Paracetamol protocol \_\_\_\_\_
- First Aid kit list \_\_\_\_\_
- Blister Management sheet \_\_\_\_\_
- Medication administration form \_\_\_\_\_
- Other: \_\_\_\_\_