

# Epidermolysis Bullosa Health and Emergency Care Plan

Attach photo  
for easier  
identification  
(optional)

## Supplementary Documentation for Day Care and Pre-School Healthcare 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 day care or pre-school environment. This plan should be used in consultation with parents, carers, EB clinical staff and centre 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):

## Day Care or Pre-School

Name of Centre:

Manager:

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 day care / pre-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 day care / pre-school first aider after discussion with primary treating team and parents:

## Key Contact Details

Clinical Nurse:

Class aide / support worker:

Other key contacts:



# Epidermolysis Bullosa Plan for Day Care and Pre-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.
- Paint or felt pens instead of crayons or pencils will be gentler on my hands.
- I will need some help with my creative work at day care or pre-school.
- Please use a protective glove or bandage over my hand dressings so that I can still get dirty with play, then change the cover afterwards.

Parent or teacher comments:

## Section 2 : Eating / Food Preparation

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

Name of staff member:

### Section 3 : Toileting

- No to assistance.
- Yes, to needing assistance that differs from my peer's developmental abilities with toileting while I am day care or pre-school.

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 always need full assistance with all aspects of toileting.
- Other:

### Section 4 : Uniform

- No to assistance.
- Yes, to needing changes to my day care 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 Centre Manager to agree on options of less abrasive / softer / low friction items that will be considered acceptable day care or pre-school attire.

- Shoes (open sandals, mesh 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).
- Shoe free time may be important in hot weather, or when I have sores on my feet.  
Rooms where I can safely do this include:

- 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 centre.

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 centre. If I am tripped or knocked over I may develop blistering or a large wound. This will need to be cleaned as outlined under section 9. 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 news/visitors/movies or shows.
- When I have lots of wounds or blisters, I might need assistance to mobilise around the day care or pre-school.

Options to assist with my mobility, as discussed with my specialist treating team include:

## 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 day care or pre-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. Extra staffing may need to be considered for these events.
- 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, day care or pre-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 demonstrate behaviours that show I am unhappy about my dressings or scars which may affect my emotional well-being and development.
- As a family, we are happy for other families to be told about our child's needs and 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 day care or pre-school, please contact:  

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- 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 verbally complain I am sore, or I may withdraw or cry due to pain.
  - 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 : Dressings and Wound care

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

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

- I need assistance from the person trained in helping me with blister management while I am at day care or pre-school.
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- I would like you to call my parents if any wound care is required while I am at day care or pre-school.

- I have my own carer / staff member with me at day care or pre-school who can assist me with everything.

- I have a communication book that should be used for any first aid or wound care needs attended to while I am at day care or pre-school.

- The dressings that I use on wounds if I need attention at day care or pre-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):

Centre Manager:

Room Teacher:

Aide:

## Documents attached

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