



Back to Community-Epidermolysis Bullosa

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What is Epidermolysis Bullosa (EB)?

- A rare connective tissue disorder
- Shares the most well-known symptom of extremely fragile skin that blisters and tears from minor friction or trauma.
- Internal organs and bodily systems can also be seriously affected by the disease.



Large blister over palms



Scarring resulting in contracture and fusion of fingers



Chronic wound over feet

Child development

Healthy development means that children of all abilities, including those with **special health care needs**, are able to grow up where their **social, emotional and educational needs** are met.

Objectives



- 1) To provide adequate planning and arrangement before admission to hostel.
- 2) To resolve complex care issue during stay in the hostel.
- 3) To monitor the physical and psychological condition of the child during and after stay in the hostel.
- 4) To encourage collaboration between Burns Centre and the school.

Methodology

- Hold a meeting among staff of school, MSW and Burn nurses
- Burn nurses have on-site visit in the hostel
- Modification of facilities recommended



Conduct sharing session to nursing staff in Burns Centre

LEARN
SHARE
RN

Prepare educational video for specific wound care on EB for school nurses

- Handover memo to school
- Weekly phone follow up
- Regular wound monitoring by CNS and Burn Nurse Consultant

To: _____
From: Burns Centre, PHN
Date: _____

Progress note: _____

Wound Condition and dressing regimen: _____

Please receive the following items:

A. Dressing: <input type="checkbox"/> Mepitel One (20cm x 20cm) _____ pcs <input type="checkbox"/> Polyurea Silver _____ pcs <input type="checkbox"/> _____	B. Gauze supplement: <input type="checkbox"/> En-wrap _____ cm <input type="checkbox"/> En-wrap plus _____ packs <input type="checkbox"/> Gauze plus _____ packs
C. Medication: <input type="checkbox"/> Medication for _____ days/weeks <input type="checkbox"/> Medication administration record printout	D. Others: <input type="checkbox"/> Subcut Uniform

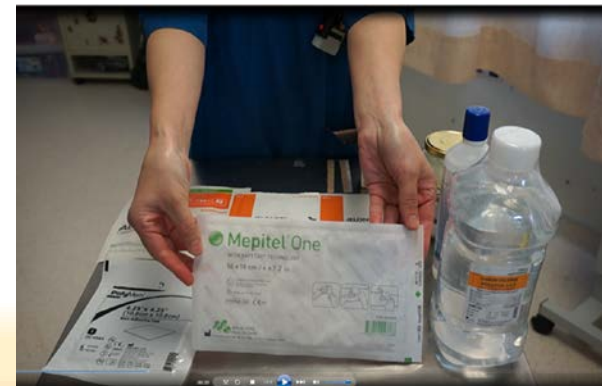
Name & Rank of Nurse: _____ Signature: _____

This part is to be completed by the attending nurse. Please kindly return to Burns Centre afterwards.

Progress note: _____

Wound Condition and dressing regimen: _____

Name of attending nurse: _____ Signature: _____ Date: _____



Outcome and result

- Stayed in the hostel 2 days per week
- Enjoyed school activities
- Established good relationship with staff of school and hostel
- No obvious change of his body weight, fever pattern, wound and skin condition, and fingers mobility
- School nurses could provide the specific nursing care to the child



Conclusion

- Prolonged hospitalization is associated with significant social, physical and psychological burden to the patient.
- **Nurses can collaborate with the community to achieve better quality of care for the long-stay patient.**

