

# Epidermolysis Bullosa

## Antenatal Referral and Education

### Providing families and birth hospitals with EB support and newborn preventative EB management techniques.

The Provision of educational support, referral pathways and early links to disease specific clinical care are important for effective rare disease management. The National Epidermolysis Bullosa Dressings Scheme (NEBDS) can facilitate EB education, support, and links to appropriate care through the antenatal period. This can help to alleviate parental anxiety and assist health care workers establish EB specific prevention strategies.

### Contacts

#### Family Details

Name:

Expected Due Date:

EB Diagnosis (if known):

Comments

#### Primary Obstetrician or Midwife

Name:

Phone:

Email:

Comments

Continued next page

## Contacts

### Hospital of birth

Name:

Phone:

Email:

Comments

### EB Hospital for newborn care (if required)

Name:

Phone:

Email:

Comments

## Referrals to NEBDS nurse

Referrals can be made antenatally for pregnancies that requires EB support, or for a postnatal birth where a baby has been born showing signs of EB.

**Customer Care Phone:** 1300 290 400

**Email:** [eb@iagroup.org.au](mailto:eb@iagroup.org.au)

## Resource downloads

Website: <https://www.ebdressings.com.au/>

Educational material and contacts can be found by selecting 'resources' and then 'EB Baby Boxes'.

## Supporting documents

(attached as hyperlinks)

- Recommendations of care for newborn with EB:  
[https://www.ebdressings.com.au/wp-content/uploads/2020/10/NEBDS\\_RecommendedCareOfNeonatesWithEB.pdf](https://www.ebdressings.com.au/wp-content/uploads/2020/10/NEBDS_RecommendedCareOfNeonatesWithEB.pdf)
- How to handle newborn:  
[https://www.ebdressings.com.au/wp-content/uploads/2020/10/NEBDS\\_HowToHandleABaby.pdf](https://www.ebdressings.com.au/wp-content/uploads/2020/10/NEBDS_HowToHandleABaby.pdf)
- The EB Baby box:  
[https://www.ebdressings.com.au/wp-content/uploads/2020/10/NEBDS\\_BabyBoxList.pdf](https://www.ebdressings.com.au/wp-content/uploads/2020/10/NEBDS_BabyBoxList.pdf)
- Paediatric EB centres staff contact list:  
<https://www.ebdressings.com.au/wp-content/uploads/2021/08/2021.08.25-Staff-Contact-List.pdf>

## Antenatal EB Education plan

Action	Purpose	Education Provided
Request for EB antenatal education	Establish connection for EB education and support	<ul style="list-style-type: none"> <li>• Offer parents contact with Genetics team if they wish</li> <li>• Obtain email consent from Mother to make contact with birthing team</li> <li>• Discuss pregnancy and birth preparation with mother to understand; care team,</li> </ul>
Comments:		
Initial Contact	Obstetrician or midwife	<ul style="list-style-type: none"> <li>• NEBDS nurse to meet with birth team</li> <li>• NEBDS nurse to meet with family and discuss EB history</li> <li>• Obtain consent from family for NEBDS nurse and birth team to discuss care.</li> </ul>
Comments:		
Email resources	Establish an EB resource folder and dressing box	<ul style="list-style-type: none"> <li>• Recommendations of care for newborn with EB</li> <li>• How to handle newborn</li> <li>• Introduction to Baby box and contacts</li> <li>• Downloads available on NEBDS website.</li> </ul>
Comments:		
Communication during pregnancy	Contact with birth team	<ul style="list-style-type: none"> <li>• Discuss EB precautions with Manager, Educator and high-risk neonatal CNC or similar</li> <li>• Discuss possibility of normal birth, and postnatal support</li> <li>• Assist team to prepare EB box (or parent if family have access to NEBDS)</li> <li>• Access to clinical practice guidelines and literature for team to make appropriate management plan.</li> </ul>
Comments:		

## Antenatal EB Education plan continued

Action	Purpose	Education Provided
Education	Prepare for birth	<ul style="list-style-type: none"> <li>In-services available via telehealth for delivery suite team, primary carers</li> <li>Recommended time for education is 30 weeks gestation.</li> </ul>
Comments:		
Access to newborn wound care	Setting up EB dressing box	<ul style="list-style-type: none"> <li>Families who already access the dressing scheme can assist to set up their own EB box</li> <li>Tertiary hospitals may have access to appropriate stock for newborn wound care</li> <li>Local hospitals, birth centres, or postnatal referrals can organise for a newborn EB box to be couriered from Independence Australia, request via phone or email</li> <li>Contact details at bottom of page.</li> </ul>
Comments:		
Postnatal care	Link family and birthing team to EB	<ul style="list-style-type: none"> <li>Birth hospital to contact identified state centre for newborn EB care if baby born with signs of EB.</li> </ul>
Comments:		
Postnatal follow up	Close link from IA	<ul style="list-style-type: none"> <li>Summary letter to Family</li> <li>Summary letter to primary carer</li> <li>Summary letter of education provided and contact details to birthing hospital</li> <li>Summary letter to Paediatric hospital if postnatal care was referred onwards.</li> </ul>
Comments:		