independence AUSTRALIA

Resource Tool

for Epidermolysis Bullosa Wound Care and Dressings Application

National Epidermolysis Bullosa Dressing Scheme

1. Important Notices

The National Epidermolysis Bullosa Dressing Scheme is an initiative of the Australian Government

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Publication: 2nd Edition

July 2022
Second edition rewritten by Rebecca Saad (NEBDS nurse),
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C=Copyedited by workwisewords.

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1. About this document

Background

The Resource Tool for Epidermolysis Bullosa Wound Care and Dressings Application has been compiled by Independence Australia (IA) in consultation with the Clinical Advisory Committee (CAC). The Resource Tool outlines the recommended management of wound care for people with Epidermolysis Bullosa (EB) in Australia. The dressings that have been listed herein are those that are available through the National Epidermolysis Bullosa Dressing Scheme (NEBDS or the Scheme). Any products mentioned in this resource tool that are not available through the NEBDS will be highlighted as such.

The full dressing schedule is available on the Scheme's website at www.ebdressings.com.au. Good wound care and proper dressing techniques are essential in the management of EB. The roles of wound dressings in EB are to provide a barrier between the person with EB and the environment, help reduce infection, promote an optimal healing environment, relieve pain, limit friction and protect vulnerable skin from trauma.[1,2,3]

It is also paramount that non-adherent dressings are primarily used in EB due to skin fragility. No single approach to managing wounds has proved totally effective and most people with EB need a variety of wound dressings to manage their wounds. Personal preference, lifestyle and carer time can also play a part in appropriate dressing selection.[3,4]

Audience/Purpose of this document

This document outlines current recommendations based on available evidence and clinical experience in wound care management and general skin care for people with EB. The information provided in this document has been compiled using clinical experience, published clinical papers on wound care and management of EB, and manufacturers' recommendations on dressing usage. The Resource Tool is to be used as a guide by:

(a) Healthcare Professionals (HCPs) treating people with EB; and

(b) people with EB and carers of people with EB who have obtained independent professional medical advice from a Treating HCP.

Audience (project role)	Purpose of the Resource Tool
Recipients of the Scheme	Documents the clinical indications for wound dressings and how dressings should be applied
The Department of Health and Aged Care (the Department), representing the Commonwealth of Australia – provides funding for the Scheme	The dressings referred to in the Resource Tool (unless specified otherwise) are available through the Scheme
Independence Australia – responsible for administering the Scheme and improving education on optimum dressing use for HCPs	Documents the clinical practice recommendations (currently published in Australia and internationally); provides

Audience (project role)	Purpose of the Resource Tool
and people with EB on behalf of the Department	support, education and support materials based on this Resource Tool
Clinical Advisory Committee (CAC) – responsible for making recommendations to the Department through Independence Australia	Provides advice and reviews the dressing guidelines based on clinical evidence and experience with dressings and the general wound management requirements of people with EB

Acknowledgments

This document was compiled by Independence Australia in consultation with the NEBDS CAC.

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Figure 1: Diagram used with permission of Birmingham Children's Hospital EB Team, UK.

Figure 2: Photograph used with permission of Louise Stevens.

Figure 3: Photograph used with permission of Independence Australia.

Tables of Recommended Dressings: Adapted from the article Wound Management for Children with Epidermolysis Bullosa (2010) used with permission of Jacqueline Denyer, DEBRA UK.

DEBRA International: Reference to pain management, wound care, Pregnancy and Childbirth, and squamous cell carcinoma clinical practice guidelines are made within this document. These clinical practice guidelines are created by EB health professionals from around the world who volunteer their time working on panels with DEBRA International to create best practice guidelines for EB.

Current Version

The latest version of this document will be held by the Department. The Department should be contacted to check that this is the latest version (ebdressings@health.gov.au). Any copies found to be incomplete or obsolete that are not required for historical purposes should be destroyed or returned to the Department.

Public Availability

This document is published on the internet at: www.ebdressings.com.au

Contacts

Queries regarding the Scheme, including the Resource Tool and Schedule of Dressings can be made to 1300 290 400 or eb@iagroup.org.au.

2.Glossaries

Glossary of EB Terms

Term	Meaning
Autolytic debridement	The removal of non-viable tissue from a wound using the body's own moisture to rehydrate and soften eschar/slough. This is achieved with the aid of hydrogels and dressings.
Bioburden	Bacteria over the surface of the wound but not impeding wound healing.
Biofilm	A community of micro-organisms bound by a three-dimensional matrix of extracellular polymeric substances.
Colonisation	Bacteria present in significant numbers but not impairing healing.
Contamination	*see* Bioburden.
Critical colonisation	Colonisation that increases to the point where microbial imbalance occurs and healing fails to progress.
Debridement	The removal of non-viable tissue from a wound, necessary for optimal wound management.
Epithelialisation	Epithelial cells migrating across new tissue to form a barrier between the wound and the environment. Wounds show evidence of a pink margin to the wound or isolated pink islands on the surface.
Eschar	Dead dry tissue which forms a hard, dark, leathery scab.
Exudate	Protein-rich and cell-rich wound fluid.
Foams	Non-solid dressings used to manage low to heavy exudate preventing maceration of the surrounding skin. Used as a primary or secondary dressing.
Friable wound	A wound that bleeds easily.
Granulation	Highly vascularised tissue, generally red or deep pink in colour, on the surface of a wound that is healing from the base upwards.
Hydrofibres	Dressing type that absorbs wound exudate to form a gel sheet. Promotes ease of dressing change and has a soothing effect. Useful for wounds with moderate to high exudate
Hydrogels	Dressing type that facilitates debridement but requires secondary dressing. Useful for wounds with absent or minimal exudate.
Hypergranulation	Granulation tissue that is raised above the peri-wound area.
Maceration	Over-hydrated, whitish-coloured tissue due to excess moisture.
Peri-wound	Area of skin surrounding a wound.
Pruritis	Itch.
Recalcitrant	A wound that fails to respond to interventions.
Silicone products	Based on polymerised siloxanes, can be removed from fragile skin with minimal trauma and pain. Can remain in situ as a primary dressing for up to 3–4 days to protect the wound bed.

Term	Meaning
Slough	Dead, moist, soft tissue which is often cream, brown or yellow in appearance.
Wound infection	A clinical diagnosis characterised by the wound increasing in size, exudate, odour and pain due to multiplying bacteria. It is sometimes accompanied by excessive redness and swelling.

Glossary of Terms Common to the Scheme

Term	Abbreviation	Meaning
Applicant of the Scheme	Applicant	A person diagnosed with EB in the process of applying to access the Scheme and includes such a person's Authorised Representative where the context permits.
Approved Healthcare Professional	Approved HCP	A healthcare professional (specialist) with expert knowledge, skills and experience in inherited bullosa skin disorders, specifically EB. The current list of Approved Healthcare Professionals is available from Independence Australia on 1300 290 400 or email: eb@iagroup.org.au
Authorised Representative	—	A person authorised by a person and/or the legal guardian of a person, diagnosed with EB, who is able to act on behalf of that person for such things as signing for receipt of a delivery of dressings.
Clinical Advisory Committee	CAC	Committee of health professionals and consumer representative with expert knowledge, (or people with) skills and experience in inherited bullosa skin disorders, specifically EB.
Eligibility Guidelines	—	Set of criteria recommended by the CAC and approved by the Department, for applications to be assessed against, establishing Applicant eligibility to receive benefits under the Scheme.
Epidermolysis Bullosa	EB	A rare genetic disease primarily affecting children and characterised by extremely fragile and blister prone skin. Management of this disease requires frequent application of specialised dressings and bandages to reduce skin damage and the risk of infection.
National Epidermolysis Bullosa Dressing Scheme	Scheme	The Commonwealth-funded program through which the cost of dressings is subsidised for eligible applicants diagnosed with Epidermolysis Bullosa. The Scheme is administered by Independence Australia.
Recipient of the Scheme	Recipient	An Applicant who is approved to receive benefits from the Scheme and includes such a person's

Term	Abbreviation	Meaning
		Authorised Representative where the context permits.
Resource Tool for EB Wound Care and Dressings Application	Resource Tool	Compiled by IA in consultation with the CAC and owned by the Department. The Resource Tool outlines the recommended management of wound care and correct application and use of the subsidised dressings.
Schedule of Dressings	Schedule	A list of approved dressings, developed in consultation with the CAC, to be subsidised for use by Recipients of the Scheme.
Standard Order	—	A Recipient's order of required dressings which will be used each month unless an amendment is required and approved. The Standard Order is determined by treating HCP during an Applicant's application process.
Treating Healthcare Professional	Treating HCP	An Approved HCP or a nurse with experience in managing the treatment of EB.

3.Introduction

Epidermolysis Bullosa (EB) is a rare genetic disease, characterised by extremely fragile skin and mucosae, resulting in chronic wounds and blisters. There are three broad categories of EB: Simplex, Junctional and Dystrophic. Within each of these categories there are several subtypes which are both clinically and genetically different.

Management of EB wounds requires frequent application of specialised dressings to promote healing, protect wounds and reduce the risk of infection.

The dressing recommendations put forward in this Resource Tool should be considered as an initial starting point for wound care management. There is a wide range of wound dressings available on the market, however not all dressings are appropriate for treating people with EB. The dressings listed herein are those that are available through the Scheme and are considered appropriate for use on EB wounds. Not all products have the same effect on individual needs and subtypes; therefore a selection of products within each category is available in order to achieve optimal wound care management for each recipient.

4.Literature Review and Levels of Evidence

The following recommendations have been adapted from the 2017 international *Best practice guidelines: Skin and wound care in epidermolysis bullosa*.[3] A link to the full article can be found in the reference section.

Table 1. Key EB wound care recommendations

Key recommendations
EB is a lifelong disorder that requires specialist intervention and consideration to minimise complications and improve quality of life. Ideally, management should take place in a specialised centre by a multi-disciplinary team.
In severe EB the individual's ability to heal can be compromised by malnutrition, anaemia, pruritus and pain, and should be treated appropriately.
Careful skin and wound assessment should be undertaken regularly. Management must be tailored to both the type of EB and wound characteristics.
Atraumatic dressings should be used to prevent further blistering, skin and wound bed damage.
People with EB and their carers are experts in the management of their condition and their involvement is paramount.
The choice of wound management strategies should balance efficacy, patient choice and quality of life with cost-effectiveness.
Staff caring for EB patients must be trained in specific handling techniques to avoid further harm.
Blisters are not self-limiting and intact blisters should be lanced and drained.
Management of EB wounds must address issues such as critical colonisation, infection, and protection from trauma.
Every effort should be made to treat the intense pruritus seen in EB and thereby minimise scratching that leads to further skin damage.
Silicone medical adhesive removers (SMARS) should be used when removing adherent

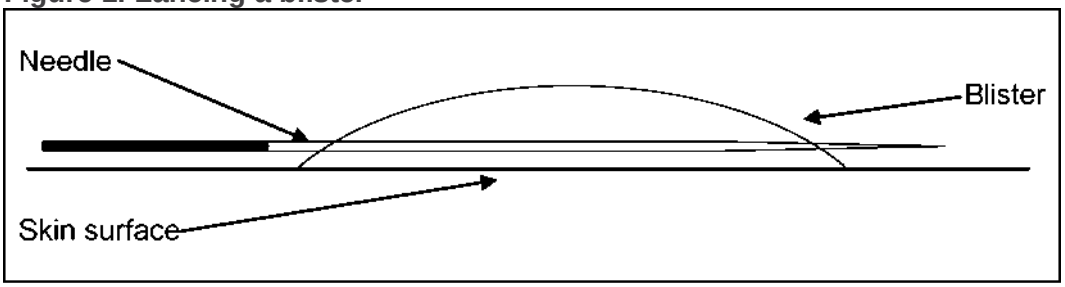
dressings or clothing.
To ensure adequate nutrition and optimise wound healing long-term, enteral feeding may be indicated in severe EB.
Optimal pain management is vital for patients with all forms of EB and include pharmacological and non-pharmacological interventions.
When a surgical or interventional procedure is indicated adjustments to anaesthesia and theatre protocols will be required to minimise skin damage and protect the airway.
The principles of wound bed preparation are applicable to wounds seen in patients with EB, particularly wounds which have become chronic.
In patients with severe forms of EB there is a high risk of squamous cell carcinoma. Regular monitoring is essential with a low threshold for biopsy of suspect areas.

Source: Adapted from Denyer, Pillay and Clapham (2017).[3]

5. Blister Management

Blisters in EB can occur spontaneously or due to friction or trauma. It is necessary to lance the blister at its lowest point (with a sterile needle or lancet, or, if not available, a sterilised sewing needle), puncturing the blister with an entrance and exit point with the needle and draining it by gently expelling the fluid. This will prevent the blister from extending further. The puncture must be big enough to allow all fluid to be drained; a second puncture site can decrease pressure while expelling fluid. Some patients choose to lance larger blisters using a sterile lancet or scissors[3] by cutting a slit into the roof of the blister, thus allowing easier drainage.

Figure 1. Lancing a blister



Source: Birmingham Children's Hospital EB Team, UK. Used with permission.

When lancing a blister:

- Wash hands
- Prepare equipment
- Clean blister with antimicrobial/antiseptic and gauze
- Insert the needle parallel to the skin,
- Insert the needle through the blister and out the opposite side, creating 2 holes in the blister.
- Repeat insertion a second time if there is a large amount of fluid to be drained.
- Remove the needle, discard in sharps container
- Gently press downwards on blister with gauze to drain all fluid inside blister
- For EB Simplex apply corn flour to dry out blister site

- For all other subtypes apply antiseptic or antimicrobial if required and dress wound/blister site with low-adherent dressing.

For EB Simplex, after lancing and draining a blister cornflour can be applied to the blister to help it dry out and prevent further blister formation from friction.[5]

For the more severe types of EB, after lancing and draining the blister a non-adherent dressing should be used to dress the area and protect the vulnerable skin.
To minimise friction, blister formation and the risk of skin/wound trauma, soft, non-sheer fabrics can be used in clothing, as well as on sleeping surfaces such as sheets and pillow cases.
Pressure redistributing mattresses may be effective for those with poor mobility and increased risk of pressure damage. Gel pads and/or foams for chairs and toilet seats also assist in alleviating pressure damage. An occupational therapist can recommend appropriate actions and products to reduce the risk of pressure damage and friction.
These products are not available through the Scheme but are considered effective in the management of EB. Contact Independence Australia or your NEBDS authorised prescriber for further information.

6.Cleansing and Bathing

Wound cleansing is one of the most important aspects of effective wound care. There remain differences in opinion on recommendations around bathing due to issues related to pain and time factors of wound management. Some individuals choose to shower, some prefer bathing and some prefer dry dressing changes that include cleaning or individual wound soaks. Regardless of the choice for cleaning the wound, the priorities should be reducing biofilm, maintaining a stable wound bed healing environment and promoting healing.

There are dressing options available on the Scheme that have a cleansing ability, such as a polymeric membrane dressing (PolyMem non-adhesive).[2,3,4] Antimicrobial washes and gels are also available on the Scheme as are silver or honey dressings. Salt (saline) baths have been advocated by some clinicians (90g in 10 litres of water).[6] There are reports that this reduces pain,[6] and bleach baths have also been suggested (5–10ml in 5 litres of water) to reduce the bacterial skin load. However, bleach residue must be rinsed off thoroughly.[7] Note that the method of cleansing and bathing from newborn period and into adulthood is a very individual choice and that cleansing and bathing can be distressing.[3,4]

Bathing a newborn (0–4 weeks) with EB birth trauma is possible but requires consideration of pain relief, clinical guidance from a multidisciplinary EB team, and consideration of the potential for further damage from handling and kicking/movement. Pain relief such as oral morphine and/or paracetamol can assist with pain management during dressing changes. Bathing with dressings intact may assist pain management for severe birth trauma. Feeding the baby after the bath while they are wrapped can calm the baby and prepare them for limb-by-limb dressing changes, using antimicrobial irrigation and saline if required.[5] Keeping the baby wrapped when possible, exposing one limb at a time, and using sucrose, breastmilk or infant formula during the dressing change can assist in calming the baby.

7.Newborn Care

Table 2. Newborn care action and rationale

Action	Rationale
At birth, if access to EB dressings is limited use commercial plastic cling film as a temporary dressing (e.g. while waiting for the dermatology and neonatal consultation).	Other materials, such as towels, may stick to the damaged skin.
Avoid attaching plastic hospital ID tags directly to a limb. Attaching to clothing or cot is preferred.	Friction of tag rubbing against skin will create blistering and trauma.
Remove cord clamp in newborns and replace with ligature.	To avoid trauma to surrounding skin.
Nurse the baby in an incubator only if medically necessary for reasons such as prematurity.	Heat can exacerbate blistering.
Ensure adequate pain relief has been given to the individual prior to skin care, dressing changes and intervention.	Dressing changes are painful and traumatic.
Wash hands prior to applying gloves and administering skin care. Non-touch/clean technique is accepted practice, rather than aseptic technique.	To prevent skin infections.
Wet the gloved fingertips with water or saline or apply 50% liquid paraffin and 50% soft paraffin to the fingertips.	To prevent fingers sticking to some dressings.
Bathing in the first few weeks of life can be delayed or carried out with dressings intact, provided adequate pain relief is used prior to the bath. Dressing changes can be done one limb at a time to avoid trauma. Dressings can be soaked off in the bath or warm saline can be used to irrigate dressings off, if required. Use a soft blanket or muslin cloth in the bath to reduce trauma if baby movement touches the edge of the bath.	Allows time for healing of damage present at birth. Movement, handling and kicking will cause further trauma.
Use a sterile needle to lance and drain all blisters. Leave the roof of the blister intact. Refer to Section 7 ‘Blister Management’.	Blisters will extend if left. The blister roof will facilitate healing and comfort.
Apply appropriate primary contact layer dressing/s to raw areas. Primary dressing may be left in place for 3–4 days. Then apply appropriate secondary dressings and secure (refer to Section 12 ‘Table of Recommended Dressings’	To protect the wound with a non-adherent dressing and to encourage healing.
Dress infant's fingers and toes individually if there is skin loss.	To avoid digital fusion of open wounds.
Avoid applying any adhesive dressings or tapes. Use non-adherent silicone tape for securing IV lines and nasogastric (NG) tubes.	Encourage oral feeding, avoid using IV lines if possible (risk of sepsis). Any adhesive dressing or tape will cause trauma.
Cleanse the nappy area with 50% liquid paraffin, 50% white soft paraffin. Avoid nappy wipes.	To avoid friction and reduce potential stinging from water.

Action	Rationale
Use a disposable nappy with a soft nappy liner or a liner cut from polar fleece (see Figure 2). Avoid cloth nappies as they rub.	To prevent edges of nappy rubbing the skin and causing further trauma.
A hydrogel impregnated dressing can be applied to the nappy and groin area if there are any wounds or raw areas.	Soothing, conformable and healing.
Wherever possible, nurse the baby in a cot laying the child on a soft pad. When lifting place arms underneath the pad and lift this together with the child. Where it is necessary to directly lift: use your hands to roll the infant onto their side, place your hands behind the infant's head and underneath the buttocks and allow the infant to roll back onto your hands and lift. Never lift a baby or child from underneath the arms.	Lifting the child on a soft pad will avoid further damage to the skin. Friction and shearing forces will cause blisters and skin loss.
Silken or soft sheets or pillow slips can be used to reduce shearing forces. Refer to Section 7 'Blister Management'.	May help prevent new trauma and blistering.
Dress babies in loose jumpsuits turned inside out. Use a soft blanket or cloth to wrap babies with limbs secure to decrease movement.	Naked babies with EB tend to cause damage to their skin by kicking their legs together and rubbing their arms across their chest. The inside-out jump suit prevents friction against the seams.
For bottle feeding, use a Pigeon cleft palate bottle or Habberman feeder if not breast fed.	To avoid further mucosal blistering due to friction on a normal feeding bottle.
Protect babies' lips and chin with 50% liquid paraffin, 50% white soft paraffin	To decrease friction from sucking the teat or nipple during feeding.

Sources: Denyer et al. (2017),[3] Gonzalez (2013),[8] Lucky et al. (2021),[9] Denyer (2009).[10]

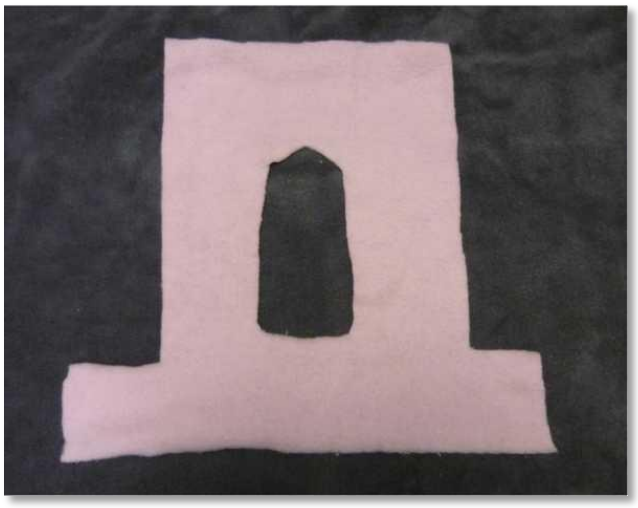


Figure 2. Nappy liner template. Can use fleece, or for hot weather, cut from a soft, dry disposable nappy liner. Source: Louise Stevens. Photograph used with permission.

Parent Education and Support

Many families confronted with a newborn with EB experience shock and guilt.[9] Comprehending a genetic disease they may not have heard of can be overwhelming. Explanations about internet photos can be important to pre-empt parents' Google searches, letting parents know that what they see online may not represent their child's journey.

Clear, simple explanations about care and referral can reassure parents. Providing information about specialty clinical services, the NEBDS service and community organisations such as DEBRA Australia can assist parents with coming to terms with the diagnosis knowing that support is available. Encourage parents to seek social and emotional support from family and friends, as they may feel disempowered in a hospital setting as they come to terms with an unexpected parenting journey.[9]

8.Principles of Wound Management in EB

General Wound Care

Wound care in EB is specific to individual wounds and to the type of EB.[2,3] Good wound care and proper dressing techniques are essential.

The roles of wound dressings in EB are to:

- provide a barrier between the individual and the environment
- help reduce infection
- provide optimal healing environment
- relieve pain
- limit friction and protect vulnerable skin from trauma.[3,7,11]

It is also paramount that non-adherent dressings are primarily used in EB due to skin fragility. A moist wound healing environment is the optimum condition to promote healing and is supported by clinical evidence.[11,12] Epithelial cells require moisture to remain viable and active. A moist wound environment allows the epithelial cells to migrate, maintains wound temperature and humidity and preserves delicate tissue.

Using both a primary and secondary dressing, where appropriate, allows for the replacement of the secondary dressing, or for the inspection of blisters, while leaving the primary dressings intact and not disturbing the fragile wound bed. The secondary dressing protects fragile skin and absorbs exudate.

No single approach to managing wounds has proved totally effective,[2] and most individuals need a variety of dressings to manage their wounds. Subtype of EB, personal preference, lifestyle and carer time can also play a part in appropriate dressings selection.[2] Product rotation may be beneficial.

Prior to dressing selection, clinical assessment of the wound bed should take place,[3] noting:

- wound edge
- peri-wound appearance/fragility
- exudate

- odour
- inflammation, evidence of infection or critical colonisation, spreading infection or systemic infection; and wound pain.

Preparation will also help the dressing change process. For example, cut templates of dressing shapes and prepare the dressings prior to bathing and cleansing. Keeping the room warm during dressing change, closing windows and turning off fans will reduce pain from circulating air.

Pain Relief

Pain relief is an important consideration, as dressing changes can be painful and distressing. Strategies should be implemented to prevent, minimise and manage both chronic and procedural pain.[3,9,11] Anticipatory anxiety prior to cleansing, dressing changes and other procedures is also common. Methods using psychological techniques such as distraction, guided imagery and coping skills can be effective in tandem with pharmacological treatments.13 In May 2022, a Coloplast wound care product, Biotain Ibu non-adhesive, was added to the NEBDS. This is the scheme's first dressing to contain ibuprofen and can contribute to reducing pain in the wound bed. Biatain Ibu is recommended as a dressing to be considered for the management of fungating wounds as topical analgesia.[3] This product requires close monitoring from a HCP to be ordered, with the need to consider age of the customer, size of the wound, and frequency of use. Customers should consult with the HCP to decide if this product is suitable.

Maintaining Optimal Healing Environment

Many wound care dressings are designed to minimise trauma and foster a moist wound environment.[11] Many are able to stay in place for up to 7 days. However, leaving an EB wound dressing intact for this long is not advocated due to malodour, potential for blister formation under dressings and the potential for infection. After a clinical diagnosis has been reached, and taking into consideration subtype requirements, dressing changes every 2–3 days are generally suggested. Certainly changing dressings too frequently will disturb the wound bed and can reignite the inflammatory phase.

Research also demonstrates that the ideal temperature conducive to healing is normal core temperature of 37°C.[4] A temperature reduction of 2°C can affect cell activity.[11] Cool cleansing solutions and frequent dressing changes reduce wound temperature and it can then take 2–3 hours before temperature returns to normal. Therefore, minimising wound exposure is advocated.[4,11] Leaving dressings in situ for up to 2–3 days optimises wound temperature stability and re-epithelialisation, saves carer time and reduces pain.[9,13] However, frequency of dressing changes is dependent on wound assessment, time available, subtype of EB and individual preference.[3]

Exudate management is crucial to avoid wetness and maceration of the wound and peri-wound area. If the dressing is not containing the exudate, then a dressing with more absorbency should be considered.[12,14] If needed the surrounding skin can be protected using a barrier film such as Welland WBF. This may help reduce trauma from dressing removal or high amounts of exudate.

Severe EB is a complex condition. Factors affecting wound healing are trauma/friction and pruritus, pain, poor nutrition, infection and anaemia.[2,3,9] It is essential that individuals are managed regularly by a consultant dermatologist and a multi-disciplinary team (such as a nurse, physiotherapist, occupational therapist, dietician and social worker). Appropriate referrals to other specialties can be made to monitor and manage the condition. All children should be managed by

a paediatrician as well as a dermatologist. Expert symptom management and the prevention of complications lead to improved quality of life.[5,9,10]

Debridement

If the wound is too dry it will lead to scab formation and healing will not be able to occur. Non-viable tissue, such as slough or eschar, creates a mechanical barrier that hinders the development of healthy tissue;[11] it also provides an attractive medium for micro-organisms. Hydrogels will donate moisture to the wound and help rehydration of the non-viable tissue. Hydrofibres can absorb slough and exudate. Both hydrogels and hydrofibre dressings contribute to autolytic debridement, a necessity for reducing build-up of biofilm that can hinder wound healing.

9. Regular Skin Checks

Squamous cell carcinomas (SCCs) can be very aggressive in individuals with EB and are the leading cause of death in recessive dystrophic EB (RDEB). Regular skin checks by a dermatologist are paramount to assess for premalignant or malignant lesions. The recommended timeframe for this group of individuals is a full skin check every 3–6 months after the age of 10 years and every 3 months from age 16 years onwards.[3,15]

Regular reviews with a HCP are a requirement of eligibility to the Scheme. This ensures that recipients' wounds are being regularly assessed and appropriate dressings and treatment actions are prescribed.

10. Wound Dressing Recommendations

All recommendations in this section are intended as a guide and should be considered as 'initial options' for treating wounds in different subtypes of EB. The following subtypes are covered:

- Simplex (localised or intermediate)
- Simplex (generalised severe)
- Junctional (intermediate)
- Junctional (severe)
- Dystrophic (recessive or dominant DEB, intermediate, or severe).

The management of critically colonised or infected lesions is discussed separately.

It is important to note that not all individuals respond in the same way to medical treatments. If appropriate maintenance or improvement in the wounds is not seen, the HCP should reassess the wound or evaluate progress.

If wounds worsen or the dressing is not tolerated, another dressing may need to be considered. If tolerance is not an issue, try a product within the same category. If there appears to be a tolerance issue, try a product from an alternative category (e.g. silicone versus non-silicone options).

If the wound worsens, consider the possibility of infection and treat accordingly.

The HCP should remember to consider recipient comfort and take recipient preference into account (where clinically appropriate) when prescribing wound care products.

Some Notes on Dressing Selections

Primary and secondary dressings

Some foam products are designed to be used as primary wound dressings, but in the more severe forms of EB these dressings can sometimes adhere to the wounds and need to be used in conjunction with a primary contact layer dressing. The primary dressing can then be left intact while lifting the secondary foam dressing to assess the wound and check the area for blistering. It can also be replaced if full of exudate.

Exudate management

Exudate is a problem when it leads to leakage, maceration, increased malodour, peri-wound skin changes, pain or infection and increases the need for dressing changes. Effective exudate management can improve healing, reduce peri-wound skin damage and infection and reduce dressing change frequency.

If daily changes are required due to excessive levels of exudate, consider changing to a more absorbent dressing – for example, a thicker foam dressing (Mepilex versus Mepilex Lite) – or to an exudate transfer dressing.

Polymeric membrane dressings (Polymem)

Polymeric membrane dressings (PMDs), such as PolymMem, are foam dressings that moisturise, cleanse, absorb and fill wounds.

When treatment is initiated, some individuals may experience a temporary increase in the level of exudate from their wounds. This may continue for the first few weeks due to the moisturising and cleansing action of the dressing. Use adhesive tape to hold the dressing in place (being careful to not have the tape touching the skin). For heavy exudate, use a more absorbent product such as PolyMem Max.

No other dressing or cream should be used on the wound in conjunction with a PMD.

Medical honey dressing (Activon Tulle)

A medical honey dressing, such as Activon Tulle, is a contact layer dressing that maintains a moist healing environment and may reduce or eliminate odours associated with wounds.

When initiating treatment, individuals may experience a temporary increase in exudate and some discomfort or pain due to osmotic pull and pH level. A barrier film (e.g. Welland WBF) can be used to avoid maceration of surrounding skin.

Preventative dressings (SPYCRA Protect)

A preventative dressing, such as SPYCRA Protect, can be used on healthy skin in areas of friction to prevent breakdown. It can also be used over newly healed skin to aid recovery or prevent new wounds occurring. Ways in which patients use preventative dressings include over heels with new shoes, under shin pads when playing soccer, and under the arms of toddlers who may be picked up or carried by adults who do not understand preventative EB techniques.

EB Simplex (generalised severe)

This is the most severe form of EB Simplex. There may be blisters present in the mouth. Finger and toe nails can also be thickened and/or missing. It can sometimes confuse clinicians in the

way it presents and infants who are severely affected are very challenging to manage.[3] EB simplex is diagnosed by the absence or decreased levels of keratin 5 or keratin 14 in the epidermis, which means that wounds and blisters are easily caused by any friction to this top layer of the skin.

Management of large areas of skin loss in newborns involves using a hydrofibre dressing secured with a tubular bandage. It is important when applying these dressings and bandages to ensure the primary dressing is exposed beyond the bandage (see Figure 3 below) to avoid blistering of the skin from the edges of both the dressing and the securing bandage.

As soon as the wounds are dry and healed, it is recommended that dressings be removed.[3] The infant should then be clothed in soft, seamless clothes or clothing with the seams worn inside out. Ongoing use of dressings after the wound has healed may exacerbate blistering.

The lancing and draining of blisters should continue and the ongoing use of cornflour will help to dry the blister and prevent friction (see Section 7 'Blister Management').[3]

Although the blistering often improves with age, this group often suffers with persistent blistering and palmar and plantar keratoderma (thickening of the skin) on the hands and soles of the feet. Ongoing consultation with dermatology and podiatry EB health professionals can assist with management.

Figure 3: Exposed primary hydrofibre dressing beyond bandage

Source: Independence Australia. Photograph used with permission.

Recommendations and Comments for Critically Colonised and Infected Wounds

Bacteria in a wound can present in four different conditions, depending on the severity: contamination, colonisation, critical colonisation, and infection.[11] Contamination is when there are bacteria over the wound surface, not impeding healing. When bacteria are present in greater numbers, but not impairing healing, the wound can be said to be colonised.[14,16]

At higher levels, the effects of bacteria can include:

- formation of biofilm and effects of biofilm
- production of toxins – destructive enzymes

- promotion of chronic inflammatory states
- promotion of increased exudate, which can then have a range of toxic effects including degrading growth factors
- pain
- malodour.[11,12,14,16,17]

When bacterial proliferation increases further it can lead to development of a biofilm layer (a layer of microorganisms, not visible to the naked eye) that prevents the wound from healing; bright, friable hypergranulation; increased exudate or slough; and raised wound margins may be seen.[14,16] Appropriate cleaning, including debridement, can reduce/remove the biofilm allowing cleaning agents and wound care products access to the wound.[11]

Enzymatic debridement, autolytic debridement and mechanical debridement are all methods of keeping the wound clean and reducing biofilm. In February 2022, debridement products Debrisoft Lolly monofilament fibre head and debridement pads were added to the NEBDs. The debridement pads, when soaked and gently wiped over the wound bed, can break down the biofilm layer. The monofilament fibre head, a similar pad, can be used in smaller, deeper or harder to reach areas.

Infection

Preventing and treating wound infection is a complex issue. If a wound is not showing signs of improvement with the current cleaning and wound care plan, professional expertise should be sought develop a new plan and further treatment if required.

Signs of wound infection include:

- friable, bright red granulation tissue
- increasing malodour
- new or increased pain or change in sensation
- epithelial bridging in granulation tissue
- delayed wound healing beyond expectations
- wound breakdown and enlargement or new ulcerations of the peri-wound.[11]

Biofilm, a layer of microorganisms that can form across a wound bed, is not visible to the naked eye and can delay healing and contribute to infection. Appropriate cleaning, including debridement, can reduce/remove the biofilm allowing cleaning agents and wound care products access to the wound.[11]

It is important to note that not all malodorous wounds or wounds with increased exudate indicate infection. Some dressings can cause a distinct odour and increase drainage of the wound (e.g. PMDs/honey dressings). Redness is often a normal part of wound healing during the inflammatory phase; however, it can also indicate re-ignition of the inflammatory phase due to trauma from the cleansing process or from dressing removal.[14,16] If a dressing adheres to the wound, which is common, moisten or soak the dressing prior to removal in order to minimise trauma to the wound bed.

Wound infection is clinically diagnosed by increased wound size, increased exudate, increased odour, increase in pain, erythema (redness) and oedema (swelling).[11,14,16] Systemic fever may also accompany a wound infection. At this stage, appropriate use of systemic antibiotics would be required, prescribed by the treating specialist or general practitioner. NEBDS wound care products are prescribed by a registered health practitioner. It is recommended that NEBDS

customers seek assistance from their prescribing health professional for any queries about infection or changes to wound management. Early intervention, including wound swab pathology tests, clinical review of the wound and assessment of suitable dressing options, can assist with wound healing.

If a wound becomes sloughy or critically colonised, attempts should be made to reduce the bacterial bioburden and promote healing with antimicrobial creams and dressings.[11,14,16] Infected or critically colonised wounds require more frequent dressing changes. Prontosan, an antimicrobial solution available on the Scheme, may be useful for cleaning and reducing biofilm[18] and can be used as a wound soak or applied as a gel directly to the wound under the dressings. Other antimicrobials, such as Flaminal[19] or honey dressings,[5,11,20] have also been shown to be effective and can assist in autolytic debridement. Honey dressings can be left in situ for 3–4 days; however, they can cause an increase in exudate. Use of a skin barrier wipe (e.g. Welland WBF) and more frequent changes of the secondary foam dressing may be required. Be mindful that these have the potential to be painful due to the osmotic pull and pH level.[5,20]

Silver dressings can also be considered for critically colonised wounds as they have a very broad antimicrobial spectrum.[11,14] The decision to prescribe these should be based on sound clinical reasons. Clinical evidence suggests that silver dressings are safe on chronic wounds when used for limited periods. In line with this, silver dressings that are available on the NEBDS are by prescription only and limited to one month's supply every three months.

Babies and children have a higher body surface area to body weight ratio and there is some new evidence to suggest that elevated serum silver levels can continue for some months in paediatric patients after discontinuing silver dressings treatment. As a result, one of the 2 National EB Centres in the UK has discontinued silver dressing use in paediatric cases. Certainly, they are not advised for children less than one year of age.[5]

If parents are concerned about possible infection in their infant or child’s wound, obtaining a wound swab from their doctor or nurse prior to commencing antimicrobial treatment is advised. Parents can then proceed with antimicrobial management while they wait for swab results. Antibiotic management can commence if required after swab results are known. For older patients managing their own wounds, if the wound has failed to improve after 7 days of topical antimicrobials it should be reassessed by the Treating HCP and the need for systemic antibiotics should be considered.[3,11]

Topical antimicrobials are not indicated for use in clean, healing wounds.[2,3,17] Maintaining a healthy wound environment and good hygiene practice – such as hand hygiene, maintaining sterility of wound dressings and cleaning/preparing the wound bed effectively – will all assist ongoing healing.

Types of Dressings

Table 3. Dressing categories and purpose

Dressing Category	Explanation
Absorbent padding	Used for protection.
Bandages and securement garments	For securing primary and secondary dressings.
Contact layer dressing	Applied directly to the wound – primary dressings.
Exudate transfer dressings	Dressing that transfers exudate away from the wound to a secondary, highly absorbent dressing.
Foam dressings	Absorbent/protective dressings. Some dressings in this category are secondary dressings which can be applied over a primary dressing.
Gauze	Useful for cleaning wounds and draining blisters.
Highly absorbent dressings	Useful in conjunction with exudate transfer dressings or alone for managing high amounts of exudate.
Hydrofibre dressing	A soft absorbent conformable dressing that absorbs exudate and turns to gel.
Hydrogels	Used for donating moisture to dry wounds.
Low absorbent dressings	Manages exudate.
Tapes	Used for securing dressings and bandages.
Needles & lancets	Used for lancing and draining blisters.
Adhesive removers and barrier film	Non-sting, gentle adhesive removers can be used directly on skin to remove dressing or tape residue. Barrier film provides a thin protective barrier between skin and dressing.
Preventative dressings	Used to protect newly healed wounds from re-trauma or healthy skin in areas prone to breaking down to prevent development of blistering or wounds (SPYCRA Protect).

Tables of Recommended Dressings

Refer to the following tables for recommended dressings for each type of EB.

Recommended Dressings – **EB SIMPLEX (localised or intermediate)**

Individuals diagnosed with Simplex rarely have moist open wounds as these usually occur during the newborn period or through trauma. Generally, older individuals may have blisters on hands and feet but the need for dressings reduces significantly.

Table 4. EBS localised or intermediate dressings

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Primary Dressing	Contact Layer Dressing - Silicone	Mepitel Atrauman Vasoline gauze	Open wounds	3–4 days	Non-adherent dressing.	Not recommended for EBS (Generalised severe) subtype as it may cause more blistering and trauma.
	Contact Layer Dressing – Non-silicone	UrgoTul	Open wounds	3–4 days	Non-adherent option for those with sensitivity to silicone.	Not suitable for very moist wounds as issues with retention of wound dressing can arise.
	Hydrofibre Dressing	AQUACEL	Open wounds	3–4 days	A soft primary dressing which may be useful if other dressings are causing blistering around the edges or not tolerated.	Cut the tubular bandage shorter than the dressing (see Figure 3).
	Exudate Transfer Dressing	Mepilex transfer	For heavily exudating wounds	Up to 3–4 days dependent on level of exudate	To assist with exudate management.	
	Hydrogels and Dressings	IntraSite Conformable	Cooling, pain reduction Sore nappy area	Replace/ re-apply when dries out	Non-adherent dressing.	Can be used to soothe and cool the feet and nappy area.
Absorption/ Protection	Foam Dressings - Silicone (Thin /Thick)	Mepilex Lite/ Mepilex Biotain Foam PolyMem	Exuding wounds and protection Can be used as primary dressing	Up to 3–4 days dependent on level of exudate	To assist with exudate management and/or give added padding to protect the area.	Can cause too much heat or cause blistering around edge of wound. If this is seen, consider the use of AQUACEL instead.

Recommended Dressings - **EB SIMPLEX (localised or intermediate) continued**

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Absorption/ Protection	Highly Absorbent Dressing	Biotain Foam	For heavy levels of exudate	Dependent on level of exudate	To be used with a contact layer/exudate transfer dressing.	
	Foam Dressings - Silicone (Thin/Thick)	Mepilex Border/Border Lite Advazorb Border ConvaTec Foam Border	Isolated wounds, provides protection	Up to 3–4 days depending on level of exudate	Assist with exudate and protects the area.	Bordered dressings should not be used on newborns. When using a bordered dressing, the use of a non-sting adhesive remover (such as Niltac or Welland) may be required to remove the dressing/s without causing trauma to the skin.
	Contact Layer Dressing – Non-silicone	UrgoTul Duo Border	Isolated wounds, provides protection			
Securement	Tubular/Dressing Fixation	Tubifast/Surgifix	To retain dressings. The type of securement is based on recipient preference (adults)	When dirty or when dressings are changed	Recommended for paediatrics as it remains firm, less likely to experience slippage, reduces friction and avoids overheating caused by excessive overlapping of crepe bandage.	Tubular bandage should be cut shorter than the dressing to avoid blistering from the edges of both the dressing and retention bandage (see Figure 3).
	Bandage – Crepe	Multicrepe			Based on individual preference.	Avoid excessive overlapping of crepe bandages to reduce the risk of overheating.
	Preventative	SPYCRA			Use over newly healed wounds to prevent breakdown.	Use over areas of high friction to prevent blister development.

Recommended Dressings - **EB SIMPLEX (generalised severe)**

Once wounds have healed and are dry, it is recommended that dressings are removed as dressings frequently lead to further blistering or may worsen the condition.

Table 5. EBS generalised severe dressings

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Primary Dressing	Hydrofibre Dressing	AQUACEL	All wounds	3–4 days	Soft, non-adherent dressing, other dressings can lead to blistering around the edges.	May coat AQUACEL dressing with 50% liquid paraffin, 50% soft paraffin prior to application.
	Hydrogel Gels and Dressings	IntraSite Conformable Sorbact	Nappy area in infants To remove slough		Cooling, conformable.	Dressing should be removed/changed before gel dries out. Be cautious of maceration. Caution should be taken to avoid maceration
Absorption/ Protection	Foam Dressings Thin – Silicone	Mepilex Lite	Exudate Provides protection		Sometimes tolerated in this group.	Foam dressings are likely to cause blistering and trauma around the edge of the dressing.
Securement	Tubular/Dressing Fixation	Tubifast/Surgifix	To retain dressing	When dirty or when dressings are changed	Recommended for paediatrics as it remains firm, less likely to experience slippage, reduces friction and avoids overheating caused by excessive overlapping of crepe bandage.	Tubular bandage should be cut shorter than the dressing to avoid blistering from the edges of both the dressing and retention bandage (see Figure 3).

	Bandage – Crepe	Multicrepe	To retain dressing The type of securement is based on individual preference (adults)		Based on individual preference.	Avoid excessive overlapping of crepe bandages to reduce the risk of overheating.
	Preventative	SPYCRA	Prevent breakdown of skin or blister development	When dirty or when dressings are changed	Protect fragile newly healed wounds from breaking down again.	Useful during daily activities that cause friction or redness to skin.

Recommended Dressings - **EB JUNCTIONAL** (intermediate)

Table 6. JEB intermediate dressings

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Primary Dressing	Contact Layer Dressing – Non-silicone	UrgoTul	Lightly exuding wound	Up to 3–4 days depending on levels of exudate	Non-adherent option for those with sensitivity to silicone.	Not recommended for very moist wounds as issues with retention of wound dressing can arise.
	Hydrofibre Dressing	Aquacel	Very moist wounds, sloughy wounds		Absorbs exudate and turns to gel.	Not suitable for low exudating wounds. Also useful on a lanced blister that has the potential to refill.
	Foam (Polymeric membrane)	PolyMem/ PolyMem Max	Recalcitrant/chronic wounds, when cleansing is required. Provides protection		Cleans the wound. A non-adherent option for those with sensitivity to silicone.	Not to be used in conjunction with other dressings, solutions, creams or gels.
	Contact Layer Dressing – Silicone/Non-silicone	Mepitel Atrauman Vasoline gauze UrgoTul	For digits	Up to 3–4 days		Can be used for larger wounds; however, Mepitel has been observed to cause some hyper-granulation in this type of EB.
Absorption/ Protection	Foam Dressings – Silicone (Thick/Thin)	Mepilex/ Mepilex Lite	To absorb exudate and provide added protection	Up to 3–4 days depending on level of exudate	If used as a secondary dressing, can be changed while leaving the primary dressing in place to protect the wound bed.	Potential difficulties with retention – caution with slippage.
	Exudate Transfer Dressing	Mepilex Transfer	To transfer exudate to absorbent dressing			
	Foam Dressings – Non-silicone (Thin)	Biatain Non-Adhesive	To absorb exudate and provide added protection			
	Foam Dressing (Thick)	UrgoCell	To absorb exudate			

Recommended Dressings - **EB JUNCTIONAL** (intermediate) continued

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Securement	Absorbent Padding	Webril/ Soffban	Extra protection (if preferred) or padding	With dressing changes or when dirty	Using this prior to applying a Tubular Bandage can assist in holding the dressings in place while applying the securing bandage.	Can cause overheating, which can encourage blistering.
	Bandages – Conforming	Handyband	Used to secure on digits		To prevent fusion of digits if wounds are open.	May coat bandage with 50% liquid paraffin/50% soft paraffin prior to application to keep fingers moist, if required.
	Bandages – Tubular Dressing Fixation	Tubifast/Surgifix	To retain dressing		Recommended for paediatrics as it remains firm, less likely to experience slippage, reduces friction and avoids overheating caused by excessive overlapping of crepe bandage.	
	Bandage – Crepe	Multicrepe	To retain dressing Type of securement is based on individual preference (adults)			Avoid excessive overlapping of crepe bandages to reduce the risk of overheating.
	Preventative	SPYCRA	Prevent breakdown of skin or blister development	When dirty or when dressings are changed	Protect fragile newly healed wounds from breaking down again	Useful for use during daily activities that cause friction or redness to skin.

Recommended Dressings - **EB JUNCTIONAL** (intermediate) continued

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Alternative Products	Contact Layer Dressing – Silicone	Mepitel Atrauman Vasoline gauze	Open wounds	Up to 3 days	Non-adherent.	While Mepitel can be used by individuals with EB Junctional, it has been observed to cause some hyper-granulation in this type of EB.
	Hydrogel Gels and Dressings	IntraSite, SoloSite & Prontosan Gels Sorbact	Can help soften/moisten/debride wounds that are dry or have eschar	Re-apply if dressing dries out	Promotes moist wound healing environment.	Cover with a secondary dressing. Be cautious of maceration.

Recommended Dressings - **EB JUNCTIONAL** (severe)

Table 7. JEB severe dressings

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Primary Dressing	Contact Layer Dressing – Non-silicone/silicone	UrgoTul Atrauman	All wounds	Up to 3–4 days depending on levels of exudate	Non-adherent.	Cover with IntraSite Conformable. **This should be the first line treatment for this type of EB.**
	Hydrofibre Dressing	Aquacel	Very moist wounds, sloughy wounds		Absorbs exudate and turns to gel.	Not suitable for low exudating wounds.
	Foam (Polymeric Membrane)	PolyMem/ PolyMem Max	When cleansing is required Provides protection		Cleans the wound and protects.	Not to be used in conjunction with other dressings, solutions, creams or gels.
	Hydrogel Gels and Dressings	IntraSite Conformable Sorbact	Nappy area in infants	With each nappy change	Cooling, conformable.	Remove prior to gel drying out.
Secondary Dressing	Hydrogel Gels and Dressings	IntraSite Conformable	All wounds	Daily or when the dressing dries out	Can be changed daily or when it dries out while leaving the primary dressing intact to protect the wound bed.	Use as a secondary dressing over UrgoTul (primary dressing). **This should be the first line treatment for this type of EB**.
Absorption/ Protection	Foam Dressings – Silicone Thin	Mepilex Lite	For protection, if required	3–4 days depending on levels of exudate		Can provide comfort and padding over AQUACEL/IntraSite if required.
	Exudate Transfer Dressing	Mepilex Transfer	Heavily exudating wounds		Conformable for difficult areas (e.g. groin, axillae).	Used to transfer exudate to absorbent dressing.
	Highly Absorbent Dressings	Relovo DryMax	Heavily exudating wounds		To absorb more exudate than foam dressings alone.	Use over a dressing such as a lighter foam or Mepilex Transfer.

Recommended Dressings - **EB JUNCTIONAL** (severe) continued

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Absorption/ Protection	Highly Absorbent Dressings	Exu-Dry/ Eclypse	Heavily exudating wounds		To absorb more exudate than foam dressings alone.	Use over secondary dressing. Can also be used, for example, to lay under the head of an infant if skin breakdown and wounds are occurring in this area.
Securement	Bandages - Tubular Dressing Fixation	Tubifast/Surgifix	To retain dressing		Reduce need for tape and adherent dressings.	Tubular bandage should be cut shorter than the dressing to avoid blistering from the edges of both the dressing and retention bandage (see Figure 3).
	Absorbent Padding	Webril/Soffban	Extra protection (if preferred) or padding	With dressing changes or when dirty		Can cause overheating and thus encourage blistering.
	Preventative	SPYCRA	Prevent breakdown of skin or blister development	With dressing changes or when dirty	Protect fragile/newly healed wounds from breaking down again	Useful during daily activities that cause friction or redness to skin.
Various		Mepitel or Atrauman/ Silflex with Mepilex Transfer or Mepilex Lite, secured with tape	Nail beds/digits		Finger and toe nails are often lost following blistering on the nail bed. Mepilex Transfer is conformable.	Avoid tapes coming in contact with the skin.
Alternatives	Hydrogel Gels and Dressings	IntraSite, SoloSite & Prontosan Gels Sorbact	Can help soften/moisten/debride wounds that are too dry or have eschar	Re-apply if dressing dries out	Promotes moist wound healing environment.	Cover with a secondary dressing. Be cautious of maceration.

Recommended Dressings - **EB DYSTROPHIC (RDEB and DDEB, moderate and severe)**

Table 8. DEB moderate severe dressings

Type of Dressing	Product Category	Product Brand	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Primary Dressing	Contact Layer Dressing – Silicone	Mepitel Atrauman	Moist wounds and for digits	3–4 days	Non-adherent.	
	Contact Layer Dressing – Non-silicone	UrgoTul	Lightly exudating wound		Non-adherent option for those with sensitivity to silicone.	Not recommended for very moist wounds as issues with retention of wound dressing can arise.
	Exudate Transfer Dressing	Mepilex Transfer	Heavily exudating wounds	Dependent on level of exudate		To transfer exudate to secondary absorbent dressing or for conformability (e.g. for digits, axillae and/or difficult to dress areas).
	Foam (Polymeric Membrane)	PolyMem/ PolyMem Max	Recalcitrant/chronic wounds, when cleansing is required. Provides protection	Up to 3–4 days depending on levels of exudate	Cleans the wound, non-adherent option for those with sensitivity to silicone.	Not to be used in conjunction with other dressings, solutions, creams or gels.
Absorption / Protection	Foam Dressings – Silicone (Thick/Thin)	Mepilex/ Mepilex Lite Biotain foam	Exudating wounds (for heavy exudate use Mepilex) or as protection for fragile skin	Up to 3–4 days depending on levels of exudate	If used as a secondary dressing, can be changed while leaving the primary dressing in place to protect the wound bed.	Can be used as a primary dressing (caution with severe EB).

Recommended Dressings - **EB DYSTROPHIC (RDEB and DDEB moderate and severe) continued**

Type of Dressing	Product Category	Product Brand	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Absorption/ Protection	Foam Dressing (Thick)	UrgoCell Biatain/ALLEVYN Heel	Exudating wounds	Up to 3–4 days depending on levels of exudate	If used as a secondary dressing, can be changed while leaving the primary dressing in place to protect the wound bed.	Potential difficulties with retention – caution with slippage.
	Highly Absorbent Dressings	DryMax/Eclypse/ Exu-Dry	For heavily exuding wounds	Depending on level of exudate	To assist in exudate management.	Avoid direct contact with wound. Use over a primary and/or secondary dressing.
Securement	Absorbent Padding	Webril/Soffban	Extra protection (if preferred) or padding or securing	With dressing changes or when dirty	In paediatrics, using this prior to applying a tubular bandage can assist to hold the dressings in place while applying the bandage.	Can cause overheating and blistering.
	Bandages – Tubular Dressing Fixation	Tubifast/Surgifix	To retain dressing. Use for paediatrics and adults		Recommended for paediatrics as it remains firm, less likely to experience slippage, reduces friction and avoids overheating caused by excessive overlapping of crepe bandage.	

Recommended Dressings - **EB DYSTROPHIC (RDEB and DDEB moderate and severe) continued**

Type of Dressing	Product Category	Product Brand	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Securement	Bandage – Crepe	Multicrepe	To retain dressing Based on individual preference (adults)			
	Bandages – Conforming	Handyband	For digits		Helps prevent fusion of digits.	
	Preventative	SPYCRA	Prevent breakdown of skin or blister development	With dressing changes or when dirty	Protect fragile/newly healed wounds from breaking down again.	Useful during daily activities that cause friction or redness to skin.
Alternatives	Contact Layer Dressing – Non-silicone	Vas Gauze ribbon/Adaptic	For digits	Up to 3 days	Helps prevent fusion of digits.	
	Bordered Dressings (Foam Silicone and Contact Layer)	Mepilex Border, Border Lite, UrgoCell, Advasorb Border Foam lite Biotain border	Isolated wounds, knees, ankles, elbows etc. or vulnerable areas	Up to 3–4 days	For protection in dominant dystrophic EB.	When using a bordered dressing, the use of an adhesive remover (such as Niltac or Welland) may be required to remove the dressings without causing trauma to the skin. Not for use on newborns.
	Hydrogel Gels and Dressings	SoloSite IntraSite Prontosan Gels Sorbact	Can help soften/moisten/debride wounds with eschar	Re-apply if dressing dries out	Promotes moist wound healing environment.	Cover with a secondary dressing. Be cautious of maceration.

Recommended Dressings – **Critically Colonised/Infected Wounds**

All EB subtypes, to be chosen in consultation with your clinical care provider.

Table 9. Dressings for infected wounds

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Primary Dressing (Honey)	Antimicrobial and Antiseptic Dressing	Activon Tulle	Malodorous wounds, critical colonisation, infection	3–4 days	May help to reduce bacterial load.	May cause stinging/discomfort. Can cause increase in wound exudate. Use barrier film (such as Welland) and highly absorbent dressing to avoid maceration of surrounding skin.
Primary Dressing (Non-silver)	Thick Foam – Non-Silicone	PolyMem	Critical colonisation		Can clean the wound.	
Primary Dressings (Silver)	Antimicrobial and Antiseptic Dressing	Acticoat 3	Drier, infected wounds where an immediate response is needed	3 days	May help to reduce bacterial load.	Use a primary contact layer first (e.g. UrgoTul, Mepitel or Silflex) if adherence to the wound becomes a problem. Moisten the Acticoat with sterile water (not saline) prior to application to keep moist. Apply IntraSite Conformable over the Acticoat to maintain moisture to dressing.
	Antimicrobial and Antiseptic Dressing	Acticoat Absorbent	For sloughy/exudating infected wounds	3–4 days depending on exudate		Be cautious of maceration. Secondary dressing not required.
	Antimicrobial and Antiseptic Dressing	Acticoat Moisture Control	For infected, heavily exuding wounds			
	Antimicrobial and Antiseptic Dressing	Mepilex AG	Infection where an adhesive but non-adherent foam is preferred and exudate management is a priority			
	Note: Restrict use of all silver dressings to prescribed time. Review wound. Avoid in infants and <1 year. Maximum use of one month every 3 months under NEBDS.					

Recommended Dressings – **Critically Colonised/Infected Wounds continued**

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Primary Dressings (Silver)	Antimicrobial and Antiseptic Dressing	Allevyn AG	Infection where a non-adhesive foam is preferred	3–4 days depending on exudate	May help to reduce bacterial load.	Caution with slippage/retention.
	Antimicrobial and Antiseptic Dressing	Biatain AG	Infection where a non-adhesive foam is preferred			Caution with slippage/retention.
	Antimicrobial and Antiseptic Dressing	Aquacel AG	EB Simplex if infected			May need a secondary dressing to absorb exudate.
	Antimicrobial and Antiseptic Dressing	PolyMem Silver	Infection where cleansing and a foam is required			
	Note: Restrict use of all silver dressings to prescribed time. Review wound. Avoid in infants <1 year. Maximum use of 1 month every 3 months under NEBDS.					
Securement	As per usual method of securement.					
Alternatives	Enzymatic Antimicrobial	Flaminal Forte	Moderate to heavy exuding wounds	In yellow/ sloughy wounds change every 1–2 days. In drier, granulating wounds change every 3–4 days	May help to reduce bacterial load.	Tubs need to be discarded after 7 days. Needs to be covered with a secondary, non-adherent dressing, as usual preference.
	Enzymatic Antimicrobial	Flaminal Hydro	Lightly exuding wounds			
	Debriding Solution	Prontosan	Where biofilm/slough is present	For wound cleansing	Can reduce biofilm to aid healing.	Warm solution prior to use. Use to rinse wound or soak gauze and place on wound for 10 mins.

Recommended Dressings – **Critically Colonised/Infected Wounds continued**

	Mechanical Debridement	Debrisoft	Where biofilm is present or build-up of crust or eschar	Removal of debris, exudate and keratosis from the wound		Use warmed cleaning solution or saline on product prior to use.

11. Roles and Responsibilities

Approved and Treating Healthcare Professionals

1. Complete the Dressing section on the Application Form (section 3) with consideration given to the recommendations contained within the Resource Tool and with reference to the Scheme's Schedule of Dressings.
2. Educate Recipients on the use of the dressings as per the manufacturer's instructions, the recommendations within the Resource Tool and the recipient's individual treatment requirements.

Independence Australia

1. Carry out NEBDS promotional and educational activities to HCPs and families living with EB, including through social media.
2. Carry out antenatal and school EB programs for customers that access the NEBDS.
3. Provide secretariat services to the CAC and the Department. Provide reporting and compliance with relevant regulatory bodies.
4. Respond to queries from Recipients and HCPs in relation to the Resource Tool and the prescribing and application of dressing available through the Scheme.
5. Provide educational material that is easy to understand for Recipients and clinically robust to allow HCPs to make informed decisions on the best dressing options available.
6. Provide clinical support to HCPs for Recipients who may have concerns with dressings that have been recommended. Including providing alternate options (to the HCPs) if current dressings are not providing desired outcomes.
7. Update the Resource Tool (as appropriate) in line with advances in treatment options (in Australia and internationally) for good wound management practice for people with EB.
8. Receive and collate applications that include research and product evidence from wound care companies that submit applications for new products to be listed on the NEBDs.

Clinical Advisory Committee (CAC)

1. Review new patient applications where diagnosis requires review, and HCP applications for authorised prescribers.
2. Provide clinical advice to establish the Resource Tool and the Schedule of Dressings.
3. Continue to provide ongoing recommendations on wound management in EB, as developments are made in Australia and internationally.
4. Meet biannually to provide clinical recommendations and advice to the Department about the Scheme, including the use and effectiveness of dressings available through the Scheme.
5. Review evidence and provide clinical expertise to provide recommendations for addition of new products to the NEBDs.

The Department

1. Review and approve the Resource Tool for EB Wound Care and Dressings Application for the National Epidermolysis Bullosa Dressing Scheme.

2. Review and approve Recipients' dressings as prescribed on Application and/or Review Forms.
3. Review and approve new patient and HCP applications and CAC recommendations for new product listings.
4. Review and approve educational materials prepared by Independence Australia.
5. Seek Government approval of new product listings with a cost.

Recipient / Authorised Representative of the Scheme

1. Utilise the prescribed dressings as directed by the treating HCP with reference to the recommendations outlined in the Resource Tool.

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Appendix A: Summary of Dressings Available on the National Epidermolysis Bullosa Dressing Scheme (NEBDS)

(Refer to the Schedule of Dressings, available at www.ebdressings.com.au for further information).

Category	Dressings
Absorbent Padding – Sterile and Nonsterile	Cotton Ortho Under Bandage Padding Soffban Absorbent Ortho Padding Webril II Undercast Padding Medipore
Bandages – Retention – Conforming – Cohesive	Easifix Conforming Retention Bandage Handyband Conforming Bandage Handygauze Cohesive retention
Bandages – Crepe, non-sterile	Multicrepe Light Crepe Bandage Multicrepe Medium Crepe Bandage Multicrepe Heavy Crepe Bandage
Bandages – Crepe, sterile	Multicrepe Medium Crepe Bandage
Bandages – Tubular/Dressing Fixation	Surgifix Tubular Elastic Net Bandage Tubifast 2-way Stretch Bandage Tubigrip Bandage
Dressing Securement Garments	Tubifast Garment Tubifast Legging Tubifast Vest Tubifast Gloves Tubifast Socks
Contact Layer Dressings – Non-silicone	Vaseline Petrolatum Gauze Adaptic Non-adhering Dressing UrgoTul UrgoTul Duo UrgoTul Duo Border
Contact Layer Dressings – Silicone	Mepitel Silicone Wound Contact Dressing Mepitel One silicone wound contact layer Atrauman silicone wound contact layer SPYCRA Film SPYCRA Protect Vellafilm
Exudate Transfer Dressings Foam Dressings – Thick, non-silicone	Mepilex Transfer Exudate Transfer Dressing ALLEVYN Heel Non-adhesive Biatain Non-adhesive Foam Dressing Biatain Soft Hold PolyMem Max Non-adhesive PolyMem Non-adhesive

Category	Dressings
	PolyMem WIC Cavity Filler UrgoCell Non-adhesive Absorbent Dressing
Foam Dressings – Thick, silicone	Mepilex Mepilex Border Mepilex Border Sacrum Mepilex Heel
Foam Dressings – Thin, silicone	Advazorb Border Mepilex Border Lite Flex Mepilex Lite
Gauze – Non-sterile and Sterile	Gauze Swabs
Highly Absorbent Dressings	Relovo DryMax Absorbent Dressing Eclypse High Absorbency Secondary Dressing Exu-Dry Absorbent Dressing Vliwasorb Pro Superabsorbent Dressing
Hydrofibre Dressings Hydrogel Gels and Dressings	AQUACEL Hydrofibre AQUACEL Foam IntraSite Conformable Hydrogel Impregnated Nonwoven Dressing IntraSite Gel Hydrogel Prontosan Wound Solution Prontosan GelX SoloSite Preserved Multi-use Hydrogel Sorbact compress Sorbact Gel UrgoClean Fibre Dressing Suprasorb G Gel Dressing Biotain Ibu
Low Absorbent Dressings	Sterile Non-woven Combine Melolin Low Adherent Melolite Low Adherent Dressing TELFA AMD Dressing TELFA Ouchless Non-adherent Dressing TELFA Non-sterile Non-adherent Dressing
Tapes – Non-silicone	Hypafix Tape Micropore Paper Tape Transpore Clear Perforated Plastic Hypo Allergenic Tape
Tapes – Silicone	Mepitac Fixation Tape Siltape Fixation Tape Kind Removal Silicone Tape Fixomull Skin Sensitive
Ancillaries – Needles and Lancets	Microfine Lancets Sterile Needles

Category	Dressings
Ancillaries – Adhesive Removers	Trio Niltac Adhesive Remover Welland Adhesive Remover Welland Barrier Film Cavillon Barrier wipes Cavillon Barrier film Cavillon Barrier cream Askina Barrier film swab
Other	Gloves Silver Lined (Pink) Prevail Pants Medium Waist

Category	Dressings
Prescription Only Items	
Honey Dressings	Activon Manuka Honey Impregnated Tulle Dressing
Silver Dressings	ALLEVYN AG Non-adhesive Dressing AQUACEL AG Dressing Biatain AG Non-adhesive Dressing Mepilex AG Dressing PolyMem Silver Max Non-adhesive Dressing PolyMem Silver Non-adhesive Dressing PolyMem Silver WIC Cavity Filler Atrauman AG Dressing
Enzymatic Antimicrobial	Flaminal Forte Flaminal Hydro
Debriding Solutions	Prontosan Wound Solution Prontosan gel Debrisoft Lolly Monofilament Fibre Debrisoft Debridement Pad