

Resource Tool

for Epidermolysis Bullosa Wound Care and Dressings Application

**National Epidermolysis Bullosa
Dressing Scheme**



Important Notices

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

Disclaimers

Publication is a general guide only

All information and material included in this publication is made available in the form of a general guide only.

This publication contains information and material of a general nature and it must not be used, interpreted or relied upon as professional medical advice, or as a substitute for getting that advice.

Any information and material in this publication must be used subject to and consistent with, the professional medical advice you have received from an independent medical expert of skin disorders. You must always seek advice from an independent medical expert of skin disorders and only rely on that advice, for the treatment of your skin condition and the latest best clinical practice, including (but not limited to) advice on how to care for wounds in your particular circumstances.

No Liability

To the extent permitted by law, the Commonwealth of Australia will not be responsible for and does not accept any liability (whether arising out of its negligence or otherwise) in respect of any injury, damages, costs, expenses and losses suffered or incurred by a person arising out of or in connection with use or reliance on anything (including (but not limited) any recommended dressings) contained in this publication.

Copyright

© Commonwealth of Australia 2018, except for Figures 1, 2, 3 and 4. Figures 1, 2, 3 and 4 are reproduced with the permission from the copyright owners.

Paper-based publications

This work is copyright. You may reproduce the whole or part of this work (including Figures 1, 2, 3 and 4) in unaltered form for your own personal use or, if you are part of an organisation, for internal use within your organisation, but only if you or your organisation do not use the reproduction for any commercial purpose and retain this copyright notice and all disclaimer notices as part of that reproduction. Apart from rights to use as permitted by the Copyright Act 1968 or allowed by this copyright notice, all other rights are reserved and you are not allowed to reproduce the whole or any part of this work in any way (electronic or otherwise) without first being given the specific written permission from the Commonwealth to do so.

Internet sites

This work is copyright. You may download, display, print and reproduce the whole or part of this work (including Figures 1, 2, 3 and 4) in unaltered form for your own personal use or, if you are part of an organisation, for internal use within your organisation, but only if you or your organisation do not use the reproduction for any commercial purpose and retain this copyright notice and all disclaimer notices as part of that reproduction. Apart from rights to use as permitted by the Copyright Act 1968 or allowed by this copyright notice, all other rights are reserved and you are not allowed to reproduce the whole or any part of this work in any way (electronic or otherwise) without first being given the specific written permission from the Commonwealth to do so.

Requests and inquiries

Requests and inquiries concerning reproduction and rights are to be sent to the Communications Branch, Department of Health, GPO Box 9848, Canberra ACT 2601, or via e-mail to copyright@health.gov.au

Table of contents

1. About this document.....	4
2. Glossary of Terms	7
3. Introduction.....	10
4. Nurse Consultant.....	10
5. Blister Management.....	10
6. Cleansing and Bathing	11
7. Newborn Care	12
8. Principles of Wound Management in EB	14
9. Regular Skin Checks	16
10. Wound Dressing Recommendations	16
11. Roles and Responsibilities	34
12. Reference List	35
Appendix A: Summary of Dressings Available on the National Epidermolysis Bullosa Dressing Scheme (NEBDS)	37

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). However, some products referred to in this Resource Tool are not listed on the Schedule of Dressings (such as Dermasilk Therapeutic Clothing).

The full dressing schedule is available on the Scheme's website www.ebdressings.com.au. Good wound care and proper dressing techniques are essential in the management of EB. The role of wound dressings in EB is to provide a barrier between the person with EB and the environment; help reduce infection; promote optimal healing environment;^{25,29} relieve pain;²⁹ limit friction and protect vulnerable skin from trauma.^{25,29}

It is also paramount that non-adherent dressings are primarily used in EB due to the skin fragility. No single approach to managing wounds has proved totally effective⁶ 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.¹⁴

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 prepared in this document has been compiled using clinical experience, published clinical papers on wound care and management of EB, as well as the 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 Healthcare Professional (HCP).

Audience (project role)	Purpose of the Resource Tool
Recipients to the Scheme	Documents the clinical indications for wound dressings and how dressings should be applied
Independence Australia - responsible for administering the Scheme, improving education of optimum dressing use on behalf of the Department to HCPs and people with EB	Documents the clinical practice recommendations (currently published in Australia and internationally), provides support, education and support materials based on this Resource Tool
CAC - responsible for making recommendations to the Department through Independence Australia	Provides advice and reviews the dressing guidelines based on clinical experience with dressings and the general wound management requirements of people with EB

Audience (project role)	Purpose of the Resource Tool
The Department of Health (Department), representing the Commonwealth of Australia - provides funding for the Scheme	The dressings referred to in the Resource Tool are only those that are available through the Scheme

Acknowledgments

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

Primary author: Louise Stevens, Clinical Nurse Consultant, BSc (Hons), RN, DipN.

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

Figure 2: nappy liner cut from polar fleece. Photograph used with permission of Louise Stevens, Independence Australia.

Figure 4: expose primary hydrofibre dressing beyond bandage. Photograph used with permission of Louise Stevens, Independence Australia.

Tables of Recommended Dressings: Concept of table format taken from the article "Wound Management for Children" used with permission of Jacqueline Denyer, DEBRA UK.

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. The NEBDS Nurse Consultant is also available to applicants, recipients, carers and HCPs at this telephone number and email address.

Levels of Evidence

It is acknowledged that in a rare condition such as EB, with the number of subtypes and clinical variants, evidence from traditional randomised controlled clinical trials in dressings and wound care management is lacking. Therefore, many recommendations must necessarily be based on consensus of opinion and clinical experience as well as individual preference, rather than high level data alone.²⁰

Within the 1995 National Health & Medical Research Council (NHMRC) Guide for the Development and Implementation of Clinical Practice Guidelines,²⁴ evidence was ranked by quality. In 1999 these levels of evidence were reviewed in the following way:

- I. Evidence obtained from a systematic review of all relevant randomised controlled trials (RCTs).
- II. Evidence obtained from at least one properly designed randomised controlled trial.
- III-1 Evidence obtained from well-designed pseudo-randomised controlled trials (alternate allocation or some other method).
- III-2 Evidence obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies), case control studies, or interrupted time series with a control group.
- III-3 Evidence obtained from comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group.
- IV. Evidence obtained from case series, either post-test or pre-test and post-test.²⁴

The purpose of clinical guidelines is to offer people with EB maximum benefit and minimum harm, and recommendations should be based on the best possible evidence. However, in the absence of empirical evidence, or where there is poor quality evidence, guidelines may contain recommendations based on findings outside the level of evidence hierarchy.²⁴

The Joanna Briggs Institute acknowledges these limitations and in 2004 developed a broader definition of what constitutes evidence (see Table 1).¹⁸ They have an inclusive approach to the development and grading of levels of evidence and implications for practice. It is acknowledged that the majority of evidence used in the compilation of this Resource Tool falls into Level 4 with some references in Level 3:

Level of Evidence	Feasibility F(1-4)	Appropriateness A(1-4)	Meaningfulness M(1-4)	Effectiveness E(1-4)	Economic Evidence
1	Metasynthesis of research with unequivocal synthesised findings	Metasynthesis of research with unequivocal synthesised findings	Metasynthesis of research with unequivocal synthesised findings	Metasynthesis (with homogeneity) of experimental studies (eg. RCT with concealed allocation) Or 1 or more large experimental studies with narrow confidence intervals	Metasynthesis (with homogeneity) of evaluations of important alternative interventions comparing all clinically relevant outcomes against appropriate cost measurement, and including a clinically sensible sensitivity analysis
2	Metasynthesis of research with credible synthesised findings	Metasynthesis of research with credible synthesised findings	Metasynthesis of research with credible synthesised findings	One or more smaller RCTs with wider confidence intervals	Evaluation of important alternative interventions comparing all clinically relevant outcomes against appropriate cost measurement, and including a clinically

Level of Evidence	Feasibility F(1-4)	Appropriateness A(1-4)	Meaningfulness M(1-4)	Effectiveness E(1-4)	Economic Evidence
					sensible sensitivity analysis
3	a. Metasynthesis of text/opinion with credible synthesised findings b. One or more single research studies of high quality	a. Metasynthesis of text/opinion with credible synthesised findings b. One or more single research studies of high quality	a. Metasynthesis of text/opinion with credible synthesised findings b. One or more single research studies of high quality	a. Cohort studies (with control group) b. Case-controlled c. Observational studies (without control group)	Evaluations of important alternative interventions comparing a limited number of appropriate cost measurement, without a clinically sensible sensitivity analysis
4	Expert opinion	Expert opinion	Expert opinion	Expert opinion, or based on physiology, bench research or consensus	Expert opinion, or based on economic theory

Table 1: Joanna Briggs Institute Levels of Evidence

2. Glossary of Terms

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/Contamination - Bacteria over the surface of the wound, not impeding wound healing.

Biofilm - Consists of a community of micro-organisms which are bound by a three-dimensional matrix of extracellular polymeric substances.

Colonised - When bacteria are present in greater numbers, but not impairing healing.

Contamination/Bioburden - Bacteria over the surface of the wound, not impeding wound healing.

Critical colonisation - When bacteria increase further, microbial imbalance occurs and the wound 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 - Effectively 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 - 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 - Facilitates debridement, require secondary dressing. Useful for wounds with absent or minimal exudate.

Hyper-granulation - 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 - Can be removed from fragile skin with minimal trauma and pain. Can remain insitu as a primary dressing for up to 3-4 days to protect the wound bed.

Slough - Dead, moist, soft tissue which is often cream, brown or yellow in appearance.

Wound Infection - Multiplying bacteria. A clinical diagnosis characterised by the wound increasing in size, exudate, odour and pain. It is sometimes accompanied with 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.

Term	Abbreviation	Meaning
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 in which the cost of dressings is subsidised for eligible applicants diagnosed with Epidermolysis Bullosa. The administration of the Scheme is provided 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 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 that have been 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. Nurse Consultant

A Nurse Consultant is available through the Scheme to provide education and support in relation to wound care and appropriate use of dressings. The NEBDS Nurse Consultant can be contacted through Independence Australia (refer to page 5 for contact details).

The role of the NEBDS Nurse Consultant is to:

- Develop and deliver educational programs and information regarding optimal use of dressings to assist people diagnosed with EB and their families to ensure that dressings are used in the most appropriate manner; and
- Support HCPs in the treatment and management of people with EB and the prescribing of appropriate dressings.

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 hypodermic needle or lancet) and drain 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 out. Some choose to lance the larger blisters using sterile scissors^{1,2} by cutting a slit into the roof of the blister, thus allowing easier drainage of the fluid.

After lancing and draining the blister in EB Simplex, cornflour is useful and can be applied to a blister to help it dry out and it also helps prevent further blister formation from friction.¹³

After lancing and draining the blister in the more severe types of EB, 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, the use of a non-shear fabric called Parafricta™ can be used. It is available in sheets and pillow slips. Fabrics such as Dermasilk® Therapeutic Clothing can also help reduce friction and itching, improve comfort^{2,34} and may assist in preventing bacterial colonisation and pruritus.¹ Silver socks and clothes impregnated with a silver thread may also help.

Pressure redistributing mattresses, such as Repose™, may be effective in 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 assist with recommending 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 for further information.

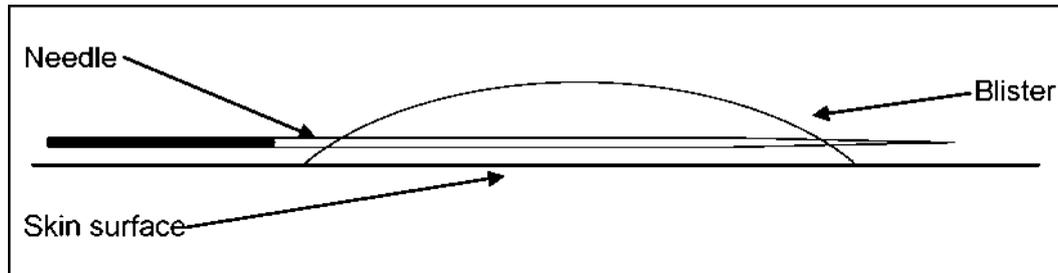


Figure 1: recommended method of blister lancing.

6. Cleansing and Bathing

Bathing is not recommended in the neonatal period (from birth to 4 weeks) in order to avoid pain, trauma and further damage from handling and kicking/movement. Limb by limb dressing changes are advocated, using irrigation and saline if required.¹³

Cleansing and bathing after the post neonatal period and into adulthood is a very individual choice and it can be distressing.¹⁴ Some individuals choose to shower and some prefer bathing, others prefer dry dressing changes, even preferring to re-dress one or two wounds each day. Others choose to take advantage of dressings that have a cleansing ability such as a polymeric membrane dressing (Polymem® non-adhesive).^{32,11,25,12,14} Salt (saline) baths have been advocated by some clinicians³ (90g in 10 litres of water). There are reports that this reduces pain.^{3,13} Bleach baths have also been suggested (5-10ml in 5 litres) to reduce the bacterial skin load. However, this must be rinsed off thoroughly.²³ Note that no comparative clinical studies have been carried out on the best method of cleansing.

7. Newborn Care

The following table outlines actions with rationales appropriate for the treatment of newborns with EB.

Action	Rationale
At birth, use commercial plastic cling film as a temporary dressing for example, whilst 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. ² Attaching to clothing or cot is preferred.	The rubbing will create blistering and trauma.
Remove cord clamp in newborns and replace with ligature. ²	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. ^{13,14}	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.
Avoid bathing in the first few weeks of life until intrauterine and birth damage have healed. Dressing changes can be done one limb at a time to avoid trauma. ¹³ Warm saline can be used to irrigate dressings off, if required.	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 5 “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. ¹³ Primary dressing may be left in place for 3-4 days. Then apply appropriate secondary dressings and secure (refer to 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. ¹³	To avoid digital fusion of open wounds.
Avoid applying any adhesive dressings or tapes. Use non-adherent silicone tape for securing IV lines and 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	To avoid friction and reduce potential

Action	Rationale
paraffin, 50% white soft paraffin. Avoid nappy wipes.	stinging from water.
Use a disposable nappy with a soft nappy liner ² 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. ^{2,13}	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. ²	Lifting the child on a soft pad will avoid further damage to the skin. Friction and shearing forces will cause blisters and skin loss.
Parafricta™ sheets or pillow slips can be used to reduce shearing forces. Refer to Section 5 "Blister Management"	May help prevent new trauma and blistering.
Dress babies in loose jumpsuits turned inside out. ²	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 infant feeding, use a Pigeon cleft palate bottle or Habberman feeder if not breast fed. ^{2,13}	To avoid further mucosal blistering due to friction on a normal feeding bottle.
Protect lips with 50% liquid paraffin, 50% white soft paraffin.	To avoid the teat sticking to the lips.



Figure 2: nappy liner cut from polar fleece.

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.^{13,14} Good wound care and proper dressing techniques are essential. The role of wound dressings in EB is to:

- Provide a barrier between the individual and the environment;
- Help reduce infection;
- Provide optimal healing environment; ^{25,29} Relieve pain; ²⁹ and
- Limit friction and protect vulnerable skin from trauma. ^{25,29}

It is also paramount that non-adherent dressings are primarily used in EB due to the skin fragility. A moist wound healing environment is the optimum condition to promote healing and is supported by clinical evidence.⁵ 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.

No single approach to managing wounds has proved totally effective⁶ and most individuals need a variety of dressings to manage their wounds. Personal preference, lifestyle and carer time can also play a part in appropriate dressings selection.¹⁴ Product rotation may be beneficial.

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.^{33,14,5,16} 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.¹⁶

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.¹³

- Prior to dressing selection, clinical assessment of the wound bed should take place,⁵ noting: Wound edge;
- Peri wound appearance/fragility;
- Exudate;
- Odour; and
- Inflammation, evidence of infection or critical colonisation, spreading infection or systemic infection; and wound pain.

It is important to note that not all malodorous wounds or wounds with increased exudate demonstrate infection. Some dressings can cause a distinct odour and increase drainage of the wound (i.e. polymeric membrane dressings/honey dressings). Redness also is often a normal part of wound healing during the inflammatory phase; however it can also indicate reignition of the inflammatory phase due to trauma from the cleansing process or from dressings removal.^{29,28} 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.

Due to modern advances in dressing technology, many dressings are designed to minimise trauma and foster a moist wound environment.^{29,28,33} 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 and the potential for infection, therefore dressing changes every 3 to 4 days are generally suggested. Certainly changing dressings too frequently will disturb the wound bed and can reignite the inflammatory phase.^{29,28}

Research also demonstrates that the ideal temperature conducive to healing is normal core temperature of 37°C.¹⁴ A temperature reduction of 2°C can affect cell activity.²¹ Cool cleansing solutions and frequent dressing changes reduces wound temperature and it can then take 2-3 hours before temperature returns to normal.²¹ Therefore, minimising wound exposure is advocated.^{5,21} Leaving dressings in situ for up to 3-4 days allows wound temperature stability, re-epithelialisation, saves carer time and reduces pain.^{13,14} However, frequency of dressing changes is dependent on wound assessment, time available and individual preference.¹³

Using both a primary and secondary dressing, where appropriate, allows for the replacement of the secondary dressing, or for the inspection of blisters, whilst leaving the primary dressings intact and not disturbing the fragile wound bed. It also enables creams (if prescribed) to be applied over the primary dressings.^{29,13} The secondary dressing protects fragile skin and absorbs exudate.

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.⁵ If needed the surrounding skin can be protected using a barrier film such as Welland Barrier Film. This may help minimise trauma from dressing removal or high amounts of exudate.¹³

Alternatively if the wound is too dry it will lead to scab formation and healing is unable to take place. Non-viable tissue, such as slough or eschar, creates a mechanical barrier which hinders the development of healthy tissue; it also provides an attractive medium for micro-organisms.²⁷ Hydrogels will donate moisture into the wound and help rehydration of the nonviable tissue. Hydrofibres can absorb slough and exudate. Both hydrogels and hydrofibre dressings contribute to autolytic debridement.

Severe EB is a complex condition. Factors affecting wound healing are trauma/friction and pruritus, poor nutrition, infection and anaemia.^{13,25} It is essential that these 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.²⁶



Sloughy wound - loose, stringy necrotic tissue, may be yellowish in colour



Granulating wound - red, beefy looking tissue



Epithelialising wound - pink to red, moist, fragile tissue that fills the wound

Figure 3: Examples of wounds.

9. Regular Skin Checks

Regular skin checks by a dermatologist are paramount in EB to assess for premalignant or malignant lesions, because squamous cell carcinomas can be very aggressive in individuals with EB. They are the leading cause of death in the Recessive Dystrophic EB type. The recommended time frame with this group of individuals is to have a full skin check every 3-6 months after the age of 10 years and every 3 months from age 16 years onwards.³⁵

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

10. Wound Dressing Recommendations

All recommendations made 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
- Simplex (Dowling Meara)
- Junctional (excluding Infant Herlitz)
- Junctional (Infant Herlitz)
- Dystrophic

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

It is important to note that not all individuals respond in the same way with 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 as it could improve results. If tolerance is not an issue try a product within the same category. If it appears to be a tolerance issue, try a product from an alternate category (for example silicone verses non-silicone options).
 - If the wound worsens, consider the possibility of infection and treat accordingly.

The HCP should remember to consider recipient comfort and give consideration to recipient preference (where clinically appropriate) when prescribing.

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, it has been found that 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 be left intact (thus protecting the wound bed) whilst lifting the secondary foam dressing to check the area for blistering and/or replacing if it is full of exudate.

Exudate management

Exudate is a problem when there is leakage, maceration, increased malodour, peri wound skin

changes, pain, 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 change to an exudate transfer dressing.

Polymeric Membrane Dressing (Polymem®):

Polymem® is a unique foam that moisturises, cleanses, absorbs and fills.

When treatment is initiated, some individuals may experience a transient 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 Transpore™ tape to hold the Polymem® in place (being careful to not have the tape touching the skin). For heavy exudate, use Polymem® Max.

No other dressing or cream should be used on the wound in conjunction with the polymeric membrane dressing.

Medical Honey Dressing (Activon Tulle):

Activon Tulle honey dressing is a contact layer dressing that maintains a moist healing environment and may reduce or eliminate odours associated with malodorous wounds.

When initiating treatment, due to osmotic pull and pH level, some individuals may experience a transient increase in exudate and some discomfort or pain. The use of a Barrier Film (Welland) could be used to avoid maceration of surrounding skin.

EB Simplex (Dowling Meara)

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 presents²⁸ and infants who are severely affected are very challenging to manage.¹³

Management of large areas of skin loss in the newborn involves using a hydrofibre dressing, secured with a tubular bandage.¹³ It is important when applying these dressings and bandages that the primary dressing is to be exposed beyond the bandage (see Figure 4 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 should be removed.¹³ The infant should then be clothed in soft, seamless clothes - or 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.¹³ Dermasilk® Therapeutic Clothing and silver impregnated clothes and socks may help comfort and reduce blistering. They may also assist in preventing bacterial colonisation if infections are frequent. These products are not available through the Scheme but are considered effective in the management of EB.

Although the blistering often improves with age, this group often suffers with persistent blistering and palmar and plantar keratoderma² (thickening of the skin) on the hands and soles of the feet.



Figure 4: expose primary hydrofibre dressing beyond bandage

Recommendations and Comments for Critically Colonised and Infected Wounds

The presence of bacteria in a wound can present in four different conditions, depending on the severity: contamination, colonisation, critical colonisation and infection.

Contamination is when there is bacteria over the wound surface, not impeding healing.

The effects of bacteria are:⁴

- Formation of biofilm and effects of biofilm
- Production of toxins - destructive enzymes
- Promotion of chronic inflammatory states
- Promotion of increased exudate can then have a range of toxic effects including degrading growth factors
- Pain
- Malodour

When bacteria are present in greater numbers, but not impairing healing, the wound can be said to be colonised.^{23,4} If bacterial proliferation increases further, the wound is unable to heal, the terms critical colonisation or local infection are used. Bright friable hypergranulation, increased exudate or slough and raised wound margins may be seen.^{4,5}

Wound infection can be defined as the clinical syndrome of bacteria and other microbial organisms impairing wound healing. Wound infection is clinically diagnosed by increased wound size, increased exudate, increased odour, increase in pain, erythema (redness) and oedema (swelling).²³ Systemic fever may also accompany a wound infection.⁵ At this stage, appropriate use of systemic antibiotics would be required, prescribed by the treating specialist or general practitioner.

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.²³ Infected or critically colonised wounds require more frequent dressing changes.¹³ Prontosan® may be useful for cleaning and reducing the biofilm.¹⁹ Antimicrobials such as Flaminal®³⁷ or Honey

dressings^{13,17,23} 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.^{13,17,23} Use of a skin barrier wipe (i.e. Welland barrier film) and changing the secondary foam dressing more frequently may be needed. Be mindful that they have the potential to be painful due to the osmotic pull and pH level.^{13,17,23}

Silver dressings can also be considered as they have a very broad antimicrobial spectrum. Questions have been raised regarding the use of silver in wound care and clinical randomised trials supporting their use are sparse. Other evidence is predominately in-vitro (laboratory tested).⁷

There is some evidence to suggest that elevated serum silver levels could occur in individuals who have been treated with silver dressings, but this has not been associated with signs of overt toxicity.³⁶ There is also evidence to suggest that silver deposits have been noted in organs after silver dressing use,³⁶ the long-term effects of this are not fully known.

However, silver dressings remain an important part of managing infected wounds.^{7,36} The decision to prescribe them should be based on sound clinical reasons. Clinical evidence suggests that silver dressings are safe on chronic wounds when used for limited periods, for example up to 4 weeks.⁷ In line with this, silver dressings that are available on the NEBDS are by prescription only and limited to 1 month's supply every 3 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 paediatrics after discontinuing silver dressings treatment. As a result of this, one of the two National EB Centres in the UK has discontinued silver dressing use in paediatrics. Certainly they are not advised for children less than 1 year of age.¹³

If the wound has failed to improve after 7-10 days of topical antimicrobials,¹⁵ the wound should be reassessed by the Treating Healthcare Professional and the possible need for systemic antibiotics should be considered.^{4,27} If infection is suspected based on clinical features, a swab should be taken for testing.^{23,27} Appropriate antibiotic treatment should be commenced, in conjunction with topical antimicrobials²⁷ and altered accordingly when swab result is available.²³

It is important to note that antimicrobial agents have the potential to inhibit cell growth and may therefore affect healing.¹⁵ More extensive research is needed to evaluate the best methods for using antimicrobials.²⁷

Topical antimicrobials are not indicated for use in clean, healing wounds.⁴

Types of Dressings

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
Hydrofiber 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 securement of 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

Table of Recommended Dressings

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

Recommended Dressings - EB SIMPLEX (excludes Dowling Meara)

Note that these guidelines apply to all EB Simplex subtypes except Dowling Meara.

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.

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Primary Dressing	Contact Layer Dressing - Silicone	Mepitel ^{®8,20,29,13}	Open wounds	3-4 days	Non-adherent dressing.	Not recommended for Dowling Meara subtype ¹³ as it may cause more blistering and trauma.
	Contact Layer Dressing - Silicone	Silflex ³³	Open wounds			
	Contact Layer Dressing - Nonsilicone	Urgotul ^{®13}	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. ¹³
	Hydrofiber 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 4).
	Exudate Transfer Dressing	Mepilex [®] Transfer ^{8,20,29,13}	For heavily exuding 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 ^{®9,20,29,13} Episil Absorbent	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. ¹³ If this is seen, consider the use of Aquacel [®] instead.

Recommended Dressings - EB SIMPLEX (excludes Dowling Meara)

Note that these guidelines apply to all EB Simplex subtypes except Dowling Meara.

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.

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Absorption / Protection	Highly Absorbent Dressing	Dry Max / Exu-Dry / Eclipse	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 ¹³	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. ²²
		Advazorb Border				
Contact Layer Dressing - Nonsilicone	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 4).
	Bandage - Crepe	Multicrepe			Based on individual preference.	Avoid excessive overlapping of crepe bandages to reduce the risk of overheating.

Recommended Dressings - EB SIMPLEX (Dowling Meara)

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.¹³

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Primary Dressing	Hydrofibre Dressing	Aquacel® ¹³	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 ¹³	Nappy area in infants		Cooling, conformable.	
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 4).
	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.

Recommended Dressings - EB JUNCTIONAL (excluding Infant Herlitz)

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Primary Dressing	Contact Layer Dressing - Nonsilicone	Urgotul ^{®9,31,13}	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 ^{®9,13}	Very moist wounds, sloughy wounds		Absorbs exudate and turns to gel.	Not suitable for low exuding wounds. ¹³ Also useful on a lanced blister that has the potential to refill.
	Foam (Polymeric membrane)	Polymem [®] / Polymem [®] Max ^{13,32,11,25,12}	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 [®] or Vas Gauze ribbon	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 ^{9,13,20,29}	To absorb exudate and provide added protection	Up to 3-4 days dependent on level of exudate	If used as a secondary dressing, these dressings can be changed whilst leaving the primary dressing in place to protect the wound bed.	
	Exudate Transfer Dressing	Mepilex [®] Transfer ^{9,13,20,29}	To transfer exudate to absorbent dressing			
	Foam Dressings - Non-silicone (Thin)	Biatain [®] Non-Adhesive	To absorb exudate and provide added protection			Potential difficulties with retention - caution with slippage.
	Foam Dressing (Thick)	Urgocell	To absorb exudate			

Recommended Dressings - EB JUNCTIONAL (excluding Infant Herlitz)

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Securement	Absorbent Padding	Webrill / 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™	For fingers. 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 The type of securement is based on individual preference (adults)			Avoid excessive overlapping of crepe bandages to reduce the risk of overheating.

Recommended Dressings - **EB JUNCTIONAL** (excluding Infant Herlitz)

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Alternative Products	Contact Layer Dressing - Silicone	Mepitel®	Open wounds	Up to 3 days		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	Can help soften/moisten/debride wounds that are dry or have eschar	Re-apply if dressing dries out	Encourages moist wound healing environment.	Cover with a secondary dressing. ²⁹ Be cautious of maceration.

Recommended Dressings - EB JUNCTIONAL (Infant Herlitz)

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Primary Dressing	Contact Layer Dressing - Nonsilicone	Urgotul ^{®9,31,13}	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 ^{®9,13}	Very moist wounds, sloughy wounds		Absorbs exudate and turns to gel.	Not suitable for low exuding wounds. ¹³
	Foam (Polymeric membrane)	Polymem [®] / Polymem [®] Max ^{13,32,11,25,12}	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 ^{9,13}	Nappy area in infants	With each nappy change	Cooling, conformable.	
Secondary Dressing	Hydrogel Gels and Dressings	Intrasite Conformable ^{9,13}	All wounds	Daily or when the dressing dries out	Can be changed daily or when it dries out, whilst 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, dependent on levels of exudate		Can provide comfort and padding over Aquacel [®] /intrasite if required.
	Exudate Transfer Dressing	Mepilex [®] Transfer ^{29,13}	Heavily exuding wounds		Conformable for difficult areas i.e. groin, axillae.	Used to transfer exudate to absorbent dressing.
	Highly Absorbent Dressings	Dry-Max	Heavily exuding wounds		To absorb additional exudate than foam dressings alone.	Use over a dressing such as a lighter foam or Mepilex [®] Transfer.

Note: Urgotul & Intrasite Conformable should be the first line dressing choice for this type of EB.

Recommended Dressings - EB JUNCTIONAL (Infant Herlitz)

Type of Dressing	Product Category	Product Brands	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Absorption / Protection	Highly Absorbent Dressings	Exu-Dry / Eclipse ⁹	Heavily exudating wounds		To absorb additional 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			Tubular bandage should be cut shorter than the dressing to avoid blistering from the edges of both the dressing and retention bandage (see Figure 4).
	Absorbent Padding	Webrill / Soffban®	Extra protection (if preferred) or padding	With dressing changes or when dirty		Can cause overheating and therefore encourage blistering.
Various		Mepitel®/ Silflex ^{9,13} 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 ²⁹	Can help soften / moisten / debride wounds that are too dry or have eschar	Re-apply if dressing dries out	Encourages moist wound healing environment.	Cover with a secondary dressing. Be cautious of maceration.

Recommended Dressings - EB DYSTROPHIC

Type of Dressing	Product Category	Product Brand	Indication and/or wound characteristic	Wear Time (Days)	Rationale	Notes
Primary Dressing	Contact Layer Dressing - Silicone	Mepitel ^{®10}	Moist wounds and for digits	3-4 days	Non-adherent.	
	Contact Layer Dressing - Silicone	Silflex	Moist wounds and for digits		Non-adherent.	
	Contact Layer Dressing - Non-silicone	Urgotul ^{®10}	Lightly exuding 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. ¹³
	Exudate Transfer Dressing	Mepilex [®] Transfer ¹⁰	Heavily exudating wounds	Dependent on level of exudate		To transfer exudate to secondary absorbent dressing or for conformability i.e. for digits, axillae and/or difficult to dress areas.
	Foam (Polymeric membrane)	Polymem [®] / Polymem [®] Max ^{11,12,13,25,32}	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 ¹⁰	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, these dressings can be changed whilst 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

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, these dressings can be changed whilst leaving the primary dressing in place to protect the wound bed.	Potential difficulties with retention - caution with slippage.
	Highly Absorbent Dressings	DryMax / Eclipse / Exu-Dry	For heavily exuding wounds	Depending on level of exudate	To assist in exudate management.	Avoid direct contact to wound. Use over a primary and/or secondary dressing.
Securement	Absorbent Padding	Webrill / 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™ ¹⁰ / 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

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.	
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	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) ²² may be required to remove the dressings without causing trauma to the skin. Not for use on newborns.
	Hydrogel Gels and Dressings	Solosite, Intrasite and Prontosan Gels	Can help soften / moisten / debride wounds with eschar	Re-apply if dressing dries out	Encourages moist wound healing environment.	Cover with a secondary dressing. Be cautious of maceration.

Recommended Dressings – Critically Colonised / 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 ²³	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 ³⁰	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, dependent 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 ²³	Infection where an adhesive but non-adherent foam is preferred and exudate management is a priority			
<p>Note: Restrict use of all silver dressings to prescribed time. Review wound. Avoid in infants and <1 year. Maximum use of 1 month every 3 months under NEBDS.</p>						

Recommended Dressings – Critically Colonised / Infected Wounds

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, dependent 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 ²³	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			
<p>Note: Restrict use of all silver dressings to prescribed time. Review wound. Avoid in infants and <1 year. Maximum use of 1 month every 3 months under NEBDS.</p>						
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 is present/slough	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.

11. Roles and Responsibilities

Approved and Treating Healthcare Professionals

1. Complete the Dressing section on either the Application and/or Review Forms 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. Respond to queries from Recipients and HCPs in relation to the Resource Tool and the prescribing and application of dressing available through the Scheme.
2. 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.
3. Provide clinical support to HCPs for Recipients that may have concerns with dressings that have been recommended. Including providing alternate options (to the HCPs) if current dressings are not providing desired outcomes.
4. 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.

CAC

1. Provide clinical advice to establish the Resource Tool and the Schedule of Dressings.
2. Continue to provide ongoing recommendations on wound management in EB, as developments are made in Australia and internationally.
3. Meet at least annually to provide clinical recommendations and advice to the Department about the Scheme, including the use and effectiveness of dressings available through the Scheme.

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 Recipients' dressings as prescribed on Application and/or Review Forms.

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.

12. Reference List

1. Abercrombie E, Mather C, Hon J, Graham-King P, Pillay E. Recessive Dystrophic Epidermolysis Bullosa. Part 2: Care of the Adult Patient, British Journal of Nursing (Tissue viability supplement) 2008; Vol 17(6): S6-S20.
2. Atheton D, Denyer J. Epidermolysis Bullosa: An outline for professionals. Adapted from the chapter Epidermolysis Bullosa written for Textbook of Paediatric Dermatology, edited by Harper JI, Oranje AP and Prose NS 2003.
3. Arbuckle A. Bathing for individuals with Epidermolysis Bullosa. Dermatologic Clinics Epidermolysis Bullosa Part 2 April 2010; Vol 28(2): 265-266.
4. Australian Wound Management Association Inc: Position Paper July 2009: Bacterial Impact on Wound Healing, from Contamination to Infection.
5. Australian Wound Management Association Inc: Standards for Wound Management 2nd edition March 2010.
6. Caldwell-Brown D, Gibbons S, Reid M. Nursing aspects of Epidermolysis Bullosa. A Comprehensive Approach. Basic and Clinical Aspects. Springer-Verley 1992: 281-294.
7. Cutting K, White R, Edmonds M. The Safety and Efficacy of Dressings with Silver - Addressing the Clinical Concerns. International wound journal 2007; Vol 4(2): 177-184.
8. DebRA UK. Epidermolysis Simplex (EBS) 2003.
9. Denyer J. Care and Management of Children with Junctional Epidermolysis Bullosa DebRA UK 2007.
10. Denyer J. Dystrophic Epidermolysis Bullosa (DEB) DebRA UK 2008.
11. Denyer J, Pillay E, Clapham J. The use of Polymeric Membrane Dressings in the Management of Chronic Wounds in EB. Poster presentation 2009.
12. Denyer J. Polymeric Membrane Dressings in the Management of Neonates and Infants with Severe Forms of Epidermolysis Bullosa (EB): Poster Presentation EWMA 2010.
13. Denyer J. Wound Management for Children with Epidermolysis Bullosa. Dermatologic Clinics 2010 Part 2 April 2010; Vol 28(2): 257-264.
14. Denyer J, Stevens L. Bathing in Epidermolysis Bullosa - Benefit over Trauma? Wounds UK 2010; Vol 6(2): 79-84.
15. EWMA. European Wound Management Association. Position Document Management of Wound Infection 2006.
16. Goldschneider KR, Lucky AW. Pain Management in Epidermolysis Bullosa. Dermatologic Clinics Epidermolysis Bullosa Part 2: April 2010; Vol 28(2): 273-282.
17. Hon J. Using Honey to Heal a Chronic Wound in a Patient with Epidermolysis Bullosa. British Journal of Nursing Oct 2005; Vol 14(9) Tissue Viability Supplement: S4-S12.
18. Joanna Briggs Institute. JBI Levels of Evidence; joannabriggs.edu.au, May 2010.
19. Kaehn K. An In-vitro Model for Comparing the Efficiency of Wound-Rinsing Solutions Journal of Wound Care: 2009; Vol 18(6).
20. Ly L, Su JC. Dressings used in Epidermolysis Bullosa Blister Wounds: a Review Journal of Wound Care: 2008; Vol 17(11): 482-492.
21. MacLellan DG. Chronic Wound Management. Australian Prescriber 2000; Vol 23(1): 6-9

22. Mather C, Denyer J. Removing Dressings in Epidermolysis Bullosa: *Nursing Times* 2008; 104(14) April 8-14: 46-48.
23. Mellerio JE. Infection and Colonisation in Epidermolysis Bullosa. *Dermatologic Clinics Epidermolysis Bullosa Part 2* April 2010; Vol 28(2): 267-270.
24. NHMRC (National Health & Medical Research Council). A Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines, Appendix B Designation of Levels of Evidence 1999; 56.
25. Pillay E. Investigating the Use of Polymeric Membrane Dressings on Recalcitrant Wounds in Epidermolysis Bullosa. Poster presentation.
26. Pillay E. Epidermolysis Bullosa. Part 1: Causes, Presentation and Complications; *British Journal of Nursing* 2008; Vol 17(5): 292-296.
27. Principles of Best Practice: Wound Infection in Clinical Practice: An International Consensus. London MEP Ltd 2008; www.mepltd.co.uk
28. Schober-Flores C. Epidermolysis Bullosa: A Nursing Perspective; *Dermatology Nursing* 1999; Vol 11(4): 243-256.
29. Schober-Flores C. Epidermolysis Bullosa Wound Care Pearls for the Noninfected and Infected Wounds; *Journal of the Dermatology Nurses Association* 2009; Vol 1(1):21-28.
30. Schober-Flores C. Epidermolysis Bullosa: The Challenges of Wound Care. *Dermatology Nursing* 2003; Vol 15(2):135-144.
31. Stevens LJ. Management of Epidermolysis Bullosa (EB) Skin Lesions with a Non adherent Dressing, Urgotul® Wound Practice and Research *Journal of the Australian Wound Management Association* 2009; Vol 17(2): 72-75.
32. Stevens LJ. The Management of Paediatric Epidermolysis Bullosa Lesions with Polymeric Membrane Dressings. Poster presentation AWMA 2010.
33. Timmons J, Gray D, Russell F. Silflex a Soft Silicone Wound Contact Dressing. *Wounds UK* 2009; Vol 5(22): 56-60.
34. Ude-Schoder Dr Catherine. Clothing in the Case of EB, EB House, Austria, Salzburg.
35. Venugopal SS, Murrell DF. Treatment of Skin Cancers in Epidermolysis Bullosa, *Dermatologic Clinics, Epidermolysis Bullosa* 2010; Part 2 Vol 28(2): 283-287.
36. Wang XQ, Kempf M, Mott J, et al. Silver Absorption on Burns After the Application of Acticoat: Data from Pediatric Patients and a Porcine Burn Model. *Journal of Burn Care and Research* 2009; March/April: 341-348.
37. White R. Flaminal®: a Novel Approach to Wound Bioburden Control. *Wounds UK* 2006; Vol 2(3): 64-69.

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
Bandages - Compression Bandages - Conforming	Setopress Compression Bandage Easifix® Conforming Retention Bandage Handyband™ Conforming Bandage
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	Episil Silicone Film Dressing Mepitel® Silicone Wound Contact Dressing Silflex Silicone Wound Contact Dressing
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 Polymem® Wic Cavity Filler Urgocell Non-adhesive Absorbent Dressing
Foam Dressings - Thick, silicone	Mepilex® Mepilex® Border Mepilex® Border Sacrum

Category	Dressings
	Mepilex® Heel
Foam Dressings - Thin, silicone	Advazorb Border Episil Absorbent Mepilex® Border Lite Mepilex® Lite
Gauze - Non-sterile and Sterile	Gauze Swabs
Highly Absorbent Dressings	DryMax Absorbent Dressing Eclipse High Absorbency Secondary Dressing Exu-Dry Absorbent Dressing
Hydrofiber Dressings Hydrogel Gels and Dressings	Aquacel® Hydrofibre Intrasite Conformable Hydrogel Impregnated Nonwoven Dressing Intrasite Gel Hydrogel Prontosan® Wound Solution Solosite Preserved Multi-use Hydrogel
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 Yukiban Alpha Tape
Tapes - Silicone	Mepitac® Fixation Tape Siltape Fixation Tape
Ancillaries - Needles and Lancets	Microfine Lancets Sterile Needles
Ancillaries - Adhesive Removers	Trio Niltac Adhesive Remover Welland Adhesive Remover Welland Barrier Film

Category	Dressings
Prescription Only Items	
Honey Dressings	Activon Manuka Honey Impregnated Tulle Dressing
Silver Dressings	Acticoat 3 Day Dressing Acticoat 7 Day Dressing Acticoat Absorbent Dressing Acticoat Moisture Control Dressing 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
Enzymatic Antimicrobial	Flaminal® Forte Flaminal® Hydro
Debriding Solutions	Prontosan® Wound Solution