



Pre-Budget Submission 2023

Our Ask: Invest €941k in home care, outreach care and mental health supports for children and adults with EB.

Epidermolysis bullosa (EB) is a rare genetic condition that makes a person's skin so fragile that even gentle contact can cause blistering and open wounds. Children and adults with more severe forms of EB wear bandages across most of their bodies to protect the skin and prevent infection. These bandages must be managed daily, with most people requiring a full bandage change at home at least three times each week.

Many children and adults living with EB are struggling to get access to all the services and supports they need, with people often having to fight for these services at an individual level. We are calling on Government to invest in additional acute and community supports that will meet the unique needs of these people and their families.

Create a ring-fenced fund of €786k for home nursing care for children and adults with severe EB to ensure they have access to secure and flexible care packages that adapt as their needs change over time.

Fund an EB Outreach Nurse to support adults living with EB at a cost of €75k. This role is an essential link between the hospital and community, supporting infection assessment at home and providing expert advice to families.

Increase the mental health supports available to children and adults living with EB and their families, including funding towards a clinical psychologist dedicated to supporting adults with EB at a cost of €80k.



EB Care at Home

Our Ask: Create a ring-fenced fund of €786k for home nursing care for children and adults with severe EB.

Children and adults with more severe forms of EB wear bandages across most of their bodies to protect the skin and prevent infection. These bandages must be managed daily, with most people requiring a full bandage change at home at least three times each week. While families can access a State-funded home nursing care package, many challenges exist in the long-term management of these packages, particularly a lack of ring-fenced funding and flexibility, which does not always allow for a timely increase in hours despite the complex and changing needs of people with severe EB.

The management of wounds through bandage changes is essential to prevent dangerous infections, meaning that continuity of care is vital. Yet, despite the hard work of community health teams and the agencies involved in delivering this care, these packages can be fragile, with no contingency plan and no back up if a nurse is suddenly unavailable. This is caused in part by difficulties in recruiting the nurses required to deliver this care. There must be a recognition of the difficulties for healthcare staff in delivering this complex care¹ and of the need for a continuous, trusting relationship between a family and their home care team.

Many parents still play a central role in delivering or supporting bandage changes. As this process involves intense physical pain for a child or adult with EB, it is particularly difficult² and emotionally draining³ for parents. We are therefore calling on Government to invest €786,240 in secure funding for home nursing care for children and adults with severe EB. This would provide for two nurses to deliver each bandage change, allowing parents to step away from this procedure as and when they wish to do so.

What does an EB bandage change involve?⁴

Bandage changes are a painful procedure during which blisters are burst and drained, ointments are applied, and the skin is wrapped in up to three layers of dressing.⁵ A full dressing change takes hours to complete, and the frequency and duration of these changes may increase over time. This type of care is highly complex because EB causes multiple wounds on various areas of the body which are at different stages of healing⁶.



There were days that I was hysterical during the bandage change - I was crying, screaming, shaking... and even praying, "Please someone, just help me". I even had everyone else in the room crying - my mom, my PA, the EB nurse and a student nurse. That's so not fair. I don't want to be the reason people are so upset.

Emma Fogarty, Patient Ambassador



Breakdown of costs: hiring a nurse to deliver an EB bandage change can cost up to approximately €90 p/hour. Allowing for two nurses to provide this care, the total cost would be €180 p/hour. Based on our most recent figures, 84 hours of home nursing care are required each week to meet the current needs of families across Ireland. Over 52 weeks, the total cost would be €786,240.

¹ Stevens, L.J., McKenna, S., Marty, J., Cowin, A.J., Kopecki, Z., (2014). Understanding the outcomes of a home nursing programme for patients with epidermolysis bullosa: an Australian perspective.

² Kearney S, Donohoe A, McAuliffe E., (2019). Living with Epidermolysis Bullosa: Daily Challenges and Healthcare Needs.

³ DEBRA Ireland (2012). The benefits of home nursing support in lessening the impact of EB care on the family unit.

⁴ For more insight on an EB bandage change visit www.youtube.com/watch?v=d0ZprNuHCdw, where DEBRA Ireland Patient Ambassador Emma Fogarty shares her experience.

⁵ DEBRA Ireland (2012). The benefits of home nursing support in lessening the impact of EB care on the family unit.

⁶ Stevens, L.J., McKenna, S., Marty, J., Cowin, A.J., Kopecki, Z., (2014). Understanding the outcomes of a home nursing programme for patients with epidermolysis bullosa: an Australian perspective.

EB Outreach Care and Mental Health Supports

Our Ask: Fund an EB Outreach Nurse to support adults living with EB at a cost of €75k per annum.

An EB outreach nurse has been in place in Children's Health Ireland at Crumlin since 2016, successfully providing support and advice to children with EB and their families. While this nurse has also provided support to adults, attending the EB adult clinic in St James's Hospital and accepting referrals, there is no equivalent role solely dedicated to meeting the needs of people once they reach adulthood. We are seeking to remedy this with funding for a second EB outreach nurse.

A report⁷ published in 2018 clearly identifies the key role an EB outreach nurse can play in meeting the healthcare needs of people with EB. This includes ensuring that home, hospital and community-based services are appropriately aligned, and acting as a link between the person with EB and the acute hospital setting. Crucially, an EB outreach nurse can deliver early intervention in the case of problem wounds, thereby reducing the need for hospital visits to assess wounds and possible infections. This role also empowers and educates people with EB and their families during pivotal transition periods.

Dedicated, specialist advice and support from an EB outreach nurse is invaluable to children with EB. An equivalent dedicated service should be available to them when they reach adulthood. We are therefore calling for an investment of €75,000 per annum for an EB outreach nurse post that would be based in St. James's Hospital and dedicated to supporting adults living with EB.

Our Ask: Increase the mental health supports available to people with EB and their families, including funding towards a clinical psychologist at a cost of €80k per annum.

EB can have a significant impact on the mental health of the person affected and their family. In a survey conducted by DEBRA Ireland in 2019, 72% of respondents identified the emotional impact as the third biggest challenge of living with EB, after medical challenges and healthcare support. The issues raised included feelings of isolation, despair, loneliness, an inability to cope and feelings of helplessness when a child is in pain.

A number of international studies have examined the psychological impact of living with EB, with one study finding prevalence levels of 63.6% for depression and 45.5% for anxiety among participants with EB⁸. Another study found that people living with EB and, by extension, those caring for them, had a lower health-related quality of life⁹.

Supporting people affected by EB with their mental health is crucial in helping them to cope with this serious condition. We should not wait until people are in crisis but instead make sure that the right support is easily accessible to anyone living with EB whenever they need it. We are therefore calling for increased mental health supports for people affected by EB, including an investment of €80,000 per annum towards a clinical psychologist post that would be based in St. James's Hospital and dedicated to supporting adults living with EB.

“Sometimes it feels like you have absolutely no-one. It can feel so isolating”
Claudia Scanlon, 18

⁷ Donohoe A., Kearney S., McAuliffe E., (2018). Identifying the Optimum Role and Function of an Epidermolysis Bullosa (EB) Outreach Nurse.

⁸ Margari, F. et al., (2010). Psychiatric symptoms and quality of life in patients affected by epidermolysis bullosa. *Journal of Clinical Psychology in Medical Settings*, 17(4), pp.333–339.

⁹ Angelis, A. et al., (2016). Social/economic costs and health-related quality of life in patients with epidermolysis bullosa in Europe. *The European Journal of Health Economics*, 17(S1), pp.31–42.

What is Epidermolysis Bullosa?

- Epidermolysis bullosa (EB) is an umbrella term for a group of rare genetic skin disorders¹⁰.
- It is estimated to affect 1 in every 18,000 babies born in Ireland.
- Approximately 300 Irish children and adults are living with EB.
- The major forms of inherited EB include EB Simplex (EBS), Dystrophic EB (DEB) and Junctional EB (JEB)¹¹.
- In milder forms, people experience blistering on their hands and feet, making holding objects and walking painful¹².
- More severe forms of EB can affect any part of a person's body, including internal organs¹³.
- The majority of EB specialist care in Ireland is provided by two main centres - a service for children in Children's Health Ireland at Crumlin and an adult service based in St. James's Hospital.
- EB is recognised as requiring a 'supra-specialist service' under the Dermatology Model of Care¹⁴.



Emma Fogarty, Patient Ambassador



"The nursing care available for Claudia feels as fragile as walking on thin ice, you never know when it will break, sending you right back to square one."

Liz Collins,
Parent Ambassador

About DEBRA Ireland

DEBRA Ireland was established in 1988 by families affected by EB and we remain a true patient organisation, where every decision is driven by what is best for people with the condition. We work across three core areas: Family Support - we deliver vital supports to families through home visits, the provision of wellbeing grants, peer-to-peer support and engagement with the EB medical teams; Research - we play an active role in driving research into EB, funding national and international research initiatives and working closely alongside researchers, DEBRA International, people living with EB and clinicians; Advocacy - we advocate alongside families living with EB to ensure people have access to the right services and supports at the right time.



Contact Us

- ☎ 01 412 6924
- ✉ info@debraireland.org
- 🌐 www.debraireland.org
- 🐦 @debraireland
- 📘 www.facebook.com/DEBRA.Ireland



¹⁰ Duipmans, J.C., Jonkman, M.F., (2010). Interdisciplinary management of epidermolysis bullosa in the public setting: the Netherlands as a model of care. *Dermatologic Clinics*. 28, 383-386.

¹¹ Fine, J.D., Bruckner-Tuderman, L., Eady, R.A., Bauer, E.A., Bauer, J.W., Has, C., Heagerty, A., Hintner, H., Hovnanian, A., Jonkman, M.F. and Leigh, I., (2014). Inherited epidermolysis bullosa: updated recommendations on diagnosis and classification. *Journal of the American Academy of Dermatology*, 70(6), pp.1103-1126.

¹² Dures, E., Morris, M., Gleeson, K., Rumsey, N., (2011). The psychosocial impact of epidermolysis bullosa. *Qualitative Health Research*. 21, 771-782.

¹³ Ibid.

¹⁴ HSE. National Clinical Programme for Dermatology: A Model of Care for Ireland.