

Pre-Budget Submission 2025

Making EB a priority



Our ask:

Ring-fence €600,000 for EB home nursing care and invest a further €95,000 to ensure holistic integrated care in line with the vision of Sláintecare (2021).

Epidermolysis bullosa (EB) is a genetic condition that affects the body's largest organ, the skin. People living with EB are missing the essential proteins that bind the skin's layers together, so any minor friction, movement or trauma causes it to break and blister.

Many people living with EB are struggling to access vital services and supports, with people often having to fight relentlessly to get what they need. We are calling on the Government to prioritise additional acute and regional supports to meet the unique needs of people living with or caring for someone with EB.

€600,000

Ring-fence funding for home care packages for people living with more severe forms of EB to ensure they can access vital, secure, and flexible care that adapts to their changing needs.

€20,000

Provide access to Complex Care Coordination in the community for people with EB to coordinate their care, regardless of their location.

€30,000

Increase the clinical psychologist post based in St James's Hospital from 0.25 to 0.5 WTE, allowing for a dedicated psychology post in the dermatology unit.

€45,000

Extend the Outreach Nurse Service to adults in the community by increasing the nursing post in St James's Hospital by 0.6 WTE.

Our ask:

Create a ring-fenced fund of €600,000 for home care packages for people living with more severe EB to ensure they can access vital, secure, and flexible care that adapts to their changing needs.

We request ring-fenced government funding to address critical gaps in home care for individuals with EB.

People living with EB need specialised, regular nursing care to manage wounds and infections effectively, with care routines often taking several hours daily and requiring two skilled caregivers¹.

Currently, care packages outsourced to multiple agencies lack coordination, resulting in inconsistent and unreliable service. High staff turnover disrupts continuity and quality of care, placing an undue burden on families and carers.

Additionally, Public Health Nurses are involved in only a small fraction of cases, failing to meet the overall demand².

The emotional and physical toll on families is significant, with many carers spending upwards of four hours daily on wound care³.

Parents and patients have testified about the stress of managing frequent staff changes and repeatedly training new caregivers.

“It’s really unfair, [their] body is already in such a vulnerable position, it’s really frustrating when changing the dressings is a skill that needs repetition, you need to do it again, and again, and wounds change too you know, you can’t just put in a random nurse on the rota, continuity matters”

Parent (Recessive Dystrophic EB)

We are therefore calling on the Government to ring-fence €600,000 in secure funding for home care for people with more severe EB. This would fund a nurse-led service to deliver each bandage change, allowing parents to step away from this procedure. Without adequate and reliable nursing support, the quality of life and health outcomes for EB patients are severely impacted. By redirecting funds to provide consistent, high-quality nursing model.

Our ask:

Provide €20,000 per annum to allow for access to Complex Care Coordination in relevant Regional Centres.

Care coordination for individuals with EB would act as a central point of contact and communicate needs to relevant providers, for regions not already covered by this service.

EB can affect multiple parts of the body, and a person living with more severe EB may have over 15 subspecialties involved in their care¹.

Currently, the burden of care coordination falls on patients and carers, who are already managing the medical demands of EB⁴.

At a recent Debra EB Expert Workshop, a parent of a child with Dystrophic EB spoke of the challenges in following up with numerous professionals to

ensure support. A young person with Recessive Dystrophic EB agreed and spoke of how it was a burden for their parent to manage coordination of their care in the home.

Currently, care coordination for children with life-limiting conditions exists in Ireland but is not universally available for children or adults with EB. We believe that access to care coordination should be available for EB patients, regardless of their location.

Debra is asking for approximately 0.2 WTE resources to be allocated to regions where complex care coordination for severe EB is not in place. This will alleviate the burden on families, improve engagement with services, and ensure the appropriate use of resources.

“It’s not fair on her, she has a job as well.”

Young person with EB

Our ask:

Increase funding for psychological support by €30,000 per annum.

This can expand the clinical psychologist service based in St James's Hospital from 0.25 to 0.5 WTE, allowing for a dedicated EB psychology for integrated continuity of care.

People with EB often face mobility challenges and difficulties with daily tasks, creating barriers to social and economic participation and leading to feelings of isolation⁹. These challenges can deprive them of independence and emotional connections, further diminishing their quality of life¹.

Pain is a prominent and unavoidable feature of EB, affecting 84% of patients¹⁰. Routine wound care, dressing management, and skin friction during activities contribute to this constant pain, which sharply reduces quality of life³.

The cumulative impact of coping with EB's symptoms and social implications frequently leads to mental health issues, with high rates of depression (63.6%) and anxiety (45.5%) among EB patients, far exceeding those in the general population¹⁰.

Supporting the mental health of EB patients is crucial for managing the bio-psycho-social burden of this condition. Access to appropriate

psychological services for EB patients in Ireland is limited⁷.

People with EB and their relatives have expressed a strong desire for efficient professional psychological support linked to EB medical care⁷.

Debra has attempted to fill this gap through a Counselling and Therapy Grant, which saw a 73% increase in demand from 2021 to 2022. Given the nature of EB, longer-term, specialised support is essential.

Debra is asking the government for €30,000 per annum to increase the clinical psychologist position at St. James's Hospital from 0.25 to 0.5 WTE. This funding would provide a dedicated clinical psychologist in dermatology at SJH, integrated into the multidisciplinary team.

This integration would enhance the identification of support needs for adults and eliminate the need for psychiatric screening as a resource management measure, reducing the stigma associated with accessing mental health services.

This investment will ensure that EB patients receive the psychological support necessary to improve their quality of life and better manage the complex challenges of their condition.

Our ask:

Provide €45,000 per annum to extend the EB Outreach Nurse post to adults in the community.

This is key to establishing integration of care across acute and community settings.

An EB Outreach Nurse was appointed to Children's Health Ireland (CHI) at Crumlin in 2016, this service was initially funded by Debra and later taken over by the HSE.

It has proven highly successful when adequately resourced, bridging the gap between home care and specialist support and improving care quality for EB patients¹¹.

A specialist outreach nurse can reduce hospitalisations by implementing best practices for managing complex wounds and infections at home¹. Early interventions by skilled specialists can prevent problem wounds from worsening, which reduces repeat hospitalisations¹².

The outreach nurse is a crucial information link between specialist centres and home care providers. This role ensures access to up-to-date, evidence-based information consistent with international best practices and tailored care plans¹¹. Research shows that EB patients highly value this support, as they often face challenges in sourcing accurate and reliable information regarding their physical care^{11,13}.

We propose increasing the nursing staff by 0.6 WTE at a cost of €45,000 per annum, allowing for an Outreach Nurse Service. This will ensure integrated continuity of care across acute and community settings for all who need it.

What is epidermolysis bullosa (EB)?

EB is a group of painful genetic blistering conditions that affects the body's largest organ, the skin. People living with EB are missing the essential proteins that bind the skin's layers together, so any minor friction, movement or trauma causes it to break and blister. It's debilitating. Excruciating. Relentless. A disease with no known cure.

There are four main forms of EB that vary in severity, but all carry their own life-limiting symptoms, life-long pain and, in many cases, disability.

EB can affect both the external and internal lining of the skin. EB is classified as a rare disease. An estimated 1 in 18,000 babies born in Ireland are affected by EB. On average, 300 people in Ireland have EB. The majority of EB specialist care in Ireland is provided by two main centres - a service for children in Our Children's Health at Crumlin and an adult service based in St James's Hospital.

What does an EB bandage change involve?¹²

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 dressing¹⁵. A full dressing change takes hours to complete, and the frequency and duration 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 healing¹³.

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