

Pre-Budget Submission 2024

Small ask, big impact



Our ask:

Invest €810,000 in mental health supports, outreach care and home care for people living with EB.

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 Government to invest in additional acute and community supports that will meet the unique needs of people living with or caring for someone with EB.

€80,000

Fund a **clinical psychologist** dedicated to supporting adults living with EB and develop a clear pathway for people to access specialist mental health supports in the community.

€75,000

Fund an **EB outreach nurse** to support adults living with EB, providing an essential link between the hospital and community, and supporting infection assessment at home.

€580,000

Create a **ring-fenced fund for home nursing care** for people living with more severe EB to ensure they can access secure and flexible care packages that adapt as their needs change over time.

€75,000

Fund an **EB care coordinator** to support people living with EB by acting as a central point of contact and communicating needs to relevant care providers.

Our ask:

Provide funding towards a clinical psychologist at a cost of €80,000 per annum and develop a clear pathway to access specialist mental health supports in the community.

There are four main forms of EB that vary in severity, but all carry their own life-limiting symptoms, pain and, in many cases, disability. This, accompanied by a lack of awareness and understanding of the condition, can have a profound effect on a person's mental health. In a survey conducted by Debra in 2019, people living with or caring for someone with EB spoke about experiencing feelings of isolation, despair, loneliness, an inability to cope and feelings of helplessness when a child is in pain.

“It leaves you wrecked when you have a big flare up. It's really really draining on your system as a whole.”

Aoife, living with EB simplex

A number of international studies have also examined the psychological impact of EB, with one study finding prevalence levels of 63.6% for depression and 45.5% for anxiety among participants with EB¹. Another study found that

people living with EB and, by extension, those caring for them, had a lower health-related quality of life².

Supporting people with their mental health is crucial in helping them to cope with this serious condition. Debra provides a Counselling and Therapy Grant to help fill the gaps that exist in mental health services. Demand for this grant increased by 73% between 2021 and 2022. Through this grant, people living with or caring for someone with EB can access 12 counselling sessions; however, given the nature of EB, much longer-term supports are needed.

We cannot wait until people are in crisis. We must ensure that the right support is easily accessible to people living with or caring for someone with EB whenever they need it. We are therefore calling for increased mental health supports, including an investment of €80,000 per annum towards a clinical psychologist based in St James's Hospital.

Our ask:

Fund an EB outreach nurse to support adults living with EB at a cost of €75,000 per annum.

An EB outreach nurse was appointed to Children's Health Ireland at Crumlin in 2016, but there has been no equivalent role solely dedicated to meeting the needs of people once they reach adulthood. A report³ published in 2018 clearly identified 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 living with or caring for someone 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 can also empower and educate people with EB during pivotal transition periods.

We are therefore calling for an investment of €75,000 per annum for an EB outreach nurse based in St James's Hospital and dedicated to supporting adults living with EB.

“Up to the age of 28 my mom was doing my dressings. That's not ok. That's not good enough. There were days when I was screaming in pain, and she felt she was causing it. She wasn't causing the pain; EB was.”

Emma, living with Recessive Dystrophic EB

Our ask:

Create a ring-fenced fund of €580,000 for home nursing care for people living with more severe EB.

People living with more severe 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 people 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.

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. It is caused in part by challenges in recruiting the nurses required to deliver this care. There must be a recognition of the difficulties for healthcare staff in delivering this complex care⁴ 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, it is particularly difficult⁵ and emotionally draining⁶ for parents.

We are therefore calling on Government to invest €580,000 in secure funding for home nursing care for people with more 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.

Breakdown of costs

Given the level of specialist care involved, we submit that nurses should be offered a premium rate when delivering these bandage changes. The cost of hiring a nurse would therefore be approximately €90 p/hour. Allowing for two nurses to provide this care, the total cost would be €180 p/hour. Based on our figures, 62 hours of home nursing care are required each week to meet current needs. Over 52 weeks, the total cost would be €580,320.

Our ask:

Fund an EB care coordinator to support people in the community at a cost of €75,000 per annum.

Like many rare diseases, EB can affect multiple parts of the body, and a person living with more severe EB may have over 15 subspecialties involved in their care⁷. A care coordinator can ensure that the care provided is joined up and that people can access appropriate services and information⁸. They can also work in an anticipatory way to improve outcomes⁹ and support people during important transition periods.

In one international study¹⁰, parents of children with EB expressed their wish to have the support of such a care manager, someone who could organise the medical, financial, and administrative aspects of care and arrange the multiple appointments required. This need was also recognised in an Irish

study¹¹, which identified the role such a coordinator could play in bridging the gap between community and specialist services, communicating care needs to relevant care providers and acting as a point of contact.

“It’s an unseen illness. There are times you would love help, but you can’t get it and don’t feel you can ask for it.”

Aoife, living with EB simplex

People living with or caring for someone with EB need support to manage this complex condition. We are therefore calling for an investment of €75,000 per annum for an EB care coordinator based in the community.

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 dressing¹³. 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 healing¹⁴.

1. Francesco Margari and others, 'Psychiatric symptoms and quality of life in patients affected by epidermolysis bullosa'. *Journal of Clinical Psychology in Medical Settings*, 17:4 (2010), 333-339 (337).
2. Aris Angelis and others, 'Social/economic costs and health-related quality of life in patients with epidermolysis bullosa in Europe'. *The European Journal of Health Economics*, 17:1 (2016), 31-42 (39).
3. Ann Donohoe, Sandra Kearney and Eilish McAuliffe, *Identifying the Optimum Role and Function of an Epidermolysis Bullosa (EB) Outreach Nurse* (Dublin: University College Dublin, 2018), p.6.
4. Louise J Stevens and others, 'Understanding the outcomes of a home nursing programme for patients with epidermolysis bullosa: an Australian perspective'. *International Wound Journal*, 13:5 (2016), 863-869 (867).
5. Sandra Kearney, Ann Donohoe and Eilish McAuliffe, 'Living with epidermolysis bullosa: Daily challenges and healthcare Needs'. *Health Expectations*, 23:2 (2020), 368-376 (370).
6. Debra Ireland, *The benefits of home nursing support in lessening the impact of EB care on the family unit* (Dublin: Debra Ireland, 2012), p.2.
7. Anne W Lucky and others, 'Psychosocial aspects of epidermolysis bullosa: Proceedings of the 11nd International Symposium on Epidermolysis Bullosa'. *International Journal of Dermatology*, 46:8 (2007), 809-814 (813).
8. Rare Disease UK, *Rare Disease Care Coordination: Delivering Value, Improving Services* (London: Rare Disease UK, 2013), p.8.
9. Rare Disease UK, *Rare Disease Care Coordination: Delivering Value, Improving Services* (London: Rare Disease UK, 2013), p.18.
10. Corinne van Scheppingen and others, 'The Main Problems of Parents of a Child with Epidermolysis Bullosa'. *Qualitative Health Research*, 18:4 (2008), 545-556 (550).
11. Sandra Kearney, Ann Donohoe and Eilish McAuliffe, 'Living with epidermolysis bullosa: Daily challenges and healthcare Needs'. *Health Expectations*, 23:2 (2020), 368-376 (373).
12. For more insight on an EB bandage change visit www.youtube.com/watch?v=d0ZprNuHCdw, where Debra Patient Ambassador Emma Fogarty shares her experience.
13. Debra Ireland, *The benefits of home nursing support in lessening the impact of EB care on the family unit* (Dublin: Debra Ireland, 2012), p.2.
14. Louise J Stevens and others, 'Understanding the outcomes of a home nursing programme for patients with epidermolysis bullosa: an Australian perspective'. *International Wound Journal*, 13:5 (2016), 863-869 (867).

“Mental health supports are absolutely vital... you can spend time asking ‘why me?’”

Kieran, living with EB simplex



The butterfly skin charity

We are uniting for change for everyone with skin as fragile as a butterfly wing.

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