Submission to the Department of Social Protection on the Cost of Disability

April 2026

About Debra and Epidermolysis Bullosa

Debra is the national charity dedicated to transforming the lives of people living with Epidermolysis Bullosa (EB), caring for someone with EB, or those who have been bereaved by EB. We strive to achieve this goal by providing Family Support services, and supporting research that will lead to effective treatments, and the generation of an evidence base for our advocacy work. Our vision for the future is that all families living with EB have timely access to the services and supports they need.

Epidermolysis Bullosa (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. There are four primary types of EB, Dystrophic (Recessive and Dominant, RDEB, DDEB), Junctional EB (JEB), Simplex (EBS), and Kindler (KEB), each one having a particular genetic cause of disease. While some subtypes of EB such as JEB are always symptomatically severe, there are variable levels of severity across forms with implications for the person's lived experience and need for support. The severity also impacts on access to supports and services, including access to disability payments and supports.

There are limited treatment options available and no cure for EB. Management of the condition focuses on amelioration of the symptoms (Prodinger, et al., 2019). This includes the ongoing, often painful medical management of this condition (Kearney et al., 2020; Walton et al., 2020), social exclusion due to the debilitating nature of the disease (Kearney et al., 2020), and the emotional impact of coping with this condition (Flannery et al., 2023). An estimated 1 in 18,000 babies born are affected by EB, with approximately 300 people in Ireland living with this condition.

About this submission

Debra welcomes the opportunity to contribute to this consultation on the Cost of Disability Payment. It is a much needed and timely consultation, given the ongoing cost of living challenges which are compounded for those living with a lifelong condition such as EB.

This submission was generated through two methods:

1. Analysis of the Life with EB in Ireland report (Flannery et al, 2023): an international review of quality-of-life and comparison of access to healthcare resources and

government supports. This collaborative report with the University of Limerick's Kemmy Business School was commissioned by Debra.

2. Engagement with the EB Community: people impacted by EB and people living with the condition through an online survey and focus group consultation with a total of 25 responses from the community (adult and children, those living with EB or caring for someone with EB).

Life with EB in Ireland report

Outlined below is information relevant to the Cost of Disability consultation from the Life with EB in Ireland report.

Access to specialised equipment and essential medical supplies for people living with Epidermolysis Bullosa (EB) in Ireland is inconsistent and strongly determined by disease severity. Individuals with more severe forms, such as Recessive Dystrophic EB (RDEB), can generally obtain required equipment through the EB multidisciplinary clinics, though gaps remain. However, those with less severe forms—often needing equipment or dressings for shorter periods—frequently struggle to access what they require and must rely on Debra for support.

People with milder EB types, such as EB Simplex (EBS), commonly do not receive bandages, seamless infant garments, and other critical dressing materials. Many do not qualify for a medical card or fail to meet severity thresholds, leaving them to self-fund essential wound-care supplies. This creates a group of patients whose needs fall between existing eligibility criteria, resulting in significant out-of-pocket medical costs.

Evidence from economic studies shows that EB places a substantial financial burden on individuals, families, carers, and the health system. Direct healthcare costs are consistently high across all research (avg €73,209), particularly for severe forms of EB. The most significant expenses arise from wound-care materials, followed by medication costs (EBS €17,732 per annum, moderate RDEB was €5,986. severe forms of EB, which had an average wound care and drug cost of €59,910, with a maximum cost of €89,780 and a minimum cost of €27,252). Hospitalisations and outpatient appointments represent the next highest category of direct cost. Additional financial pressures include GP visits, community health services, transport to medical care, physiotherapy, and occupational therapy.

The research highlights important system gaps:

- Limited access to affordable and appropriate bandaging and dressing materials

- Insufficient respite services
- Barriers to mental-health supports
- Limited community access to physiotherapy and occupational therapy
- Challenges accessing necessary medical equipment

These gaps demonstrate the need to evaluate whether current supports—including the proposed Cost of Disability Payment—adequately reflect the real and ongoing financial burden faced by people across all severities of EB.

Engagement with the EB community

The responses below mirror many of those outlined in the Cost of EB research and reflect the contributions of people impacted by EB and people living with the condition. It includes the experiences of those in receipt of disability payments and other supports and those who currently cannot access any payments or supports as EB is not always considered a disability. This engagement is based on the questions outlined in the submission guidelines under the following areas;

1. Extra costs in daily life

2. Supports and services

3. Transport

.4. Healthcare, equipment, and daily living

5. Education, work, and community life

6. Who should get a cost of disability payment?

7. What the payment should look like

8. Work, income, and supports

9. Priorities for government

10. Summit input

1. Extra costs in daily life

For people living with Epidermolysis Bullosa (EB) and their families, daily life is shaped by constant decision-making around pain, safety, and finances. EB is a lifelong condition where even small activities—walking to school, putting on shoes, bathing—can cause blistering, skin loss, and infection. As a result, every day brings costs that others simply do not face.

Families describe spending hundreds, and sometimes thousands, of euro on wound-care items such as bandages, dressings, sterile needles, antiseptic creams, and specialised plasters. These costs fluctuate depending on flare-ups, making budgeting impossible. Often, standard pharmacy products are unsuitable, leaving families to purchase expensive specialist items privately or "shop around" multiple pharmacies searching for supplies.

Clothing and footwear must be replaced far more frequently because seams, stitching, and hard materials can cause skin trauma. Comfortable footwear can cost significantly more, and even then may only be tolerated for short periods. Many children and adults require soft grips for pens, special socks, modified underwear, or loose clothing to prevent friction.

The home environment also becomes a site of additional cost: increased heating and cooling to manage temperature sensitivity; constant hot water for soaking wounds; fans, air conditioning units, or safe flooring and padding to reduce injury.

People also reported a lack of awareness around what supports are available.

Every one of these costs highlights that people with EB must spend money to reduce pain, prevent infections, and participate in daily life.

Community Voices

We've spent almost €2000 on plasters… We did not know about the hardship grant before.

It can be as low as €50 one month… or run into the hundreds of euro… everything from antibiotics to massive wound trauma dressings.

Medical expenses (bandaging, antibiotics, skin creams etc.)… missed work days due to blistering

Spend a fortune on footwear… need to change up my footwear regularly to avoid blistering.

Comfy shoes, underwear (constantly having to replace due to damage from bleeding or weeping blisters

2. Supports and services

EB is not automatically considered a disability due to the varying impact of the condition. This means that the support systems that should lighten these burdens

often fall short. Many individuals with EB do not have access to a medical card, despite having high and medically necessary expenses every month. Hardship applications for dressings and needles can take weeks, leaving families to shoulder immense costs in the meantime. Compounding this, some pharmacies do not stock the required items, or only stock partial supplies—forcing families into cycles of delays and stress.

Currently care packages are fulfilled for those who need them, but unfortunately there is no contingency plan when nursing staff are unavailable, which can leave the patient with no care. Additionally, if a nurse leaves their employment, there are no nurses trained in EB-care to replace them immediately, leading to lengthy periods where a person has no care, and a family member has no choice but to take on the home nursing care role. As an adult with EB gets older, home nursing care may become inadequate, as their needs become greater and often this is not recognised due to a lack of understanding/ awareness of EB. On occasion, when nursing care sometimes falls short, Debra has stepped in to cover costs of additional nursing to support families who do not have the means to cover this themselves.

Therapeutic supports such as chiropody, physiotherapy, occupational therapy, speech therapy, and counselling are either unavailable or only accessible privately. Yet each is essential: thickened toenails may require specialist care; children may need emotional and developmental supports; parents may benefit from counselling to manage the psychological load of providing complex care.

School supports are inconsistent, especially for wound management or mobility assistance. Parents describe having to intervene directly at schools because staff cannot safely manage blister care.

Many also reported not being aware of what financial supports/reliefs were available to them.

Whilst those with the most severe forms of EB reported that they could access many supports, across all responses, there is a clear need for guaranteed, streamlined access to the right medical supplies, therapeutic supports, and practical services—without delays or means-testing barriers.

Community Voices: Supports and Services

Hardship has been applied for… gloves cost €300–€400 per month and local health office doesn't want to take on the cost

I relied heavily on disability allowance but lost it due to means testing for but lost cohabitation

being financially stressed due to EB makes the condition worse and impedes healing

3. Transport

Transport is one of the most persistent and punishing additional costs. Many people with EB cannot walk long distances due to blistering and pain. Even short walks to a bus stop can cause severe skin breakdown. This results in reliance on private transport or taxis for everyday activities: attending medical appointments, getting to work, going to school, or simply meeting friends.

Taxi use becomes unavoidable, especially during flare-ups. Costs vary but accumulate quickly and unpredictably. Long-distance travel to specialist hospitals—frequently in Dublin—places a heavy financial burden on families from outside the city, who often must drive long distances due to the impracticality of public transport.

Lack of disability parking places people with EB at risk. Some individuals must arrive excessively early to secure a close parking space; others cannot attend events at all.

Many also report difficulties accessing a blue parking badge because the criteria is too narrow. This results in additional costs for parking and transport as taxis are used to avoid walking.

Transport barriers also reduce independence, limit participation in society, and can directly worsen physical health.

Community Voices: Transport

Sometimes I can't drive as my feet are too sore and I have to take a taxi or miss out.

I've to pay for car parking close... rental of mobility scooter on holidays.

4. Healthcare, equipment, and daily living

Healthcare costs touch every aspect of life with EB. GP visits are frequent due to infections, and not all medications fall under state schemes. For those without medical cards, monthly drug costs alone can exceed €200. Many adults describe delaying medical visits due to cost.

Specialist equipment—from wheelchairs and scooters to walking sticks, bathing aids, safe flooring, and cooling systems—is often paid for privately. Families adapt homes to prevent injury and manage pain, including removing door thresholds, padding furniture, installing air-conditioning, or creating safe play spaces.

The majority of people with EBS, for example, must pay for their own bandages and dressing materials as they do not qualify for a medical card, or their symptoms are not considered severe enough. This results in those patients on the margin falling short of the criteria necessary for full support.

Dental, eye, and hair-loss related costs—common due to the nature of EB—are typically not covered, further compounding financial pressure.

Daily life with EB means constant vigilance, constant care, and constant expense.

Community Voices

I've avoided the doctor or buying ointment and bandaging

I would sometimes try to beat infections myself because I could not afford antibiotics.

5. Education, work, and community life

EB affects opportunities from early childhood through adulthood. Children may be unable to participate in sports, PE, school events, or even walking in a parade due to blistering. Many experience painful exclusion simply because their skin cannot handle the physical demands.

Adults face career limitations, often unable to work in roles requiring heat exposure, prolonged standing, physical labour, or repetitive hand use. Some leave the workforce entirely or limit their hours to maintain essential supports, particularly carers' payments.

Community and social life are deeply impacted. Activities others enjoy—walking in town, attending concerts, going to the gym—can become inaccessible or require costly transport and recovery time.

EB does not only limit physical capability—it can restrict personal freedom, emotional wellbeing, and social belonging and the cost of this is hard to quantify.

Community voices

Adults face career limitations… avoided promotions due to fear of losing supports

EB limits me from doing physical or contact work… can't work in warm places.

6. Who should get a cost of disability payment?

The community overwhelmingly agrees that anyone with a clinical diagnosis of EB who needs it should qualify, without intrusive reassessments for a lifelong condition.

Fairness should consider:

- clinical severity and subtype,
- daily impact on mobility and function,
- time required for wound care,
- medical and therapeutic needs,
- participation limits in school, work, and social life.

Means testing, especially household means testing, is widely seen as unfair, damaging, and unfit for a lifelong rare condition whose costs do not decrease with income.

7. What the payment should look like

Responses reveal two main perspectives:

Universal Payment

Many argue that EB's lifelong, unpredictable nature means everyone diagnosed should receive a base payment, reflecting consistent extra costs.

Tiered or Needs-Based Payment

Others propose a system aligned with EB subtype or severity, given the variation between Simplex, Junctional, and Dystrophic EB.

Across the board, people emphasise:

- Payments should be regular (weekly or monthly).
- Payment should reflect additional costs incurred because of the disability. Supports like a medical card and guaranteed wound-care supplies are essential.

- Payments should not be influenced by employment, as people with EB should not be penalised for working when able.

There is scope to look at a base universal payment in conjunction with an additional needs system though this may be quite challenging in terms of determining allocation for additional needs.

8. Work, income, and supports

Many individuals with EB avoid increasing work hours or accepting promotions because they fear losing essential support payments. This creates a cycle where people feel trapped: unable to progress at work, yet unable to afford the costs associated with living with EB.

Some who work full-time still struggle financially because their condition is an added expense, not a choice. Others describe the emotional toll of trying to maintain their jobs while managing chronic pain and frequent medical interventions.

Current systems can feel adversarial and traumatising, especially when people with EB must justify their lifelong condition repeatedly.

9. Priorities

The most urgent priorities identified include:

- Acknowledge and address the varying needs and progressive nature of EB
- EB is a serious, chronic, incurable condition and, in line with advice from the Rare Disease Taskforce (2020), it is recommended that EB should be included in the Long-Term Illness scheme.
- Widen access to a medical card for every person with a lifelong condition that incurs extra expense.
- Guaranteed supply of appropriate dressings, needles, and wound-care products, without delays or hardship applications.
- Revision of the Disability Parking Scheme to ensure those in need are eligible for a blue badge.
- Support with transport costs including free travel and parking.
- Financial support for heating, cooling, footwear, and clothing.
- Access to specialist therapies for individuals and families.

People want a system that understands their condition and doesn't make them fight for every necessary item.

10. Summit input

The Summit must hear the lived realities of a long-term health condition

- The mental health challenges of conditions caused by isolation, trauma, and financial stress.
- The impact on family life, sibling relationships, and the emotional load on carers.
- The financial burden and distress caused by the cost of disability
- The reality that EB affects every decision—from what shoes to wear, to when to leave the house, to whether working is feasible.

People with EB want policymakers recognise the lifelong nature of the condition, and design supports that allow individuals and families not just to survive, but to participate fully in society.

Conclusion

In conclusion, the lived experiences of people with Epidermolysis Bullosa (EB) highlight the urgent need for a Cost of Disability Payment that accurately reflects the lifelong, unavoidable, and substantial costs associated with this rare condition. EB affects every aspect of daily life—physical, emotional, social, and financial—and current systems too often leave individuals and families without the support they need. Developing a Cost of Disability Payment that recognises the diversity of needs and supports a fair, accessible, and compassionate support model that recognises the complexity of EB, eliminates unnecessary barriers such as repeated assessments and means testing, and ensures timely access to medical supplies, therapies, transport supports, and financial assistance is essential. There also needs to be a robust communications campaign to ensure people are aware of what supports are available to them. By implementing meaningful reform, the Department of Social Protection can create a system that promotes dignity, independence, and full participation in society for all those living with a disability.

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