Pre-Budget 2027

Submission

LauraLynn
IRELAND'S CHILDREN'S HOSPICE

Advocacy

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Executive Summary

As Ireland's only provider of children's hospice care, LauraLynn has warmly welcomed the recent progress in addressing the commitments of the Programme for Government 2025 to (a) develop a new national policy on palliative care for children; and (b) to increase funding to children's hospice care.

A national, consultant-led specialist provider, LauraLynn delivers services nationwide through a Dublin-based hospice, regional community teams, and shared clinical roles with Children's Health Ireland hospitals, ensuring support is coordinated across settings.

Care is provided across five internationally recognised pillars: Direct Care, Symptom Management, Family Support, End-of-Life Care, and Bereavement Support.

LauraLynn in numbers:

- Receives over 130 new referrals annually
- Supports approximately 420 children and their families each year
- Provides specialist bereavement support to more than 200 families each year
- Delivers approximately 4,000 home and community visits annually
- Employs a multidisciplinary team of around 200 clinical and support staff

Demand for specialist children's hospice care is growing significantly. New Irish evidence suggests that up to 1,500 children may require specialist hospice care at any given time, double previous estimates. This highlights a substantial and previously under-recognised level of unmet need.

Despite being recognised as an essential part of the health system, children's hospice care is not funded on the same basis as adult services. **Adult hospices now receive full State funding as Section 38 organisations, while LauraLynn, Ireland's only children's hospice, receives just 27% of its core costs through statutory funding.** This creates a clear inequity in how hospice care is supported.

Budget 2027 provides a critical opportunity to place children's hospice care on a sustainable and equitable footing, ensuring that all children who require specialist hospice care can access services when and where they are needed.

To deliver certainty, stability and fairness Budget 2027 must:

- Redesignate LauraLynn to Section 38 status without delay and implement full statutory funding from 2027.
- Ring-fence funding to support the development of a new Children's Palliative Care Policy.
- Maintain and strengthen the national funding model to ensure consistent access to services across all regions.

Priority1: Urgently redesignate LauraLynn to Section 38 status and implement full statutory funding from 2027

Hospice care is recognised by the State as an essential component of the health service, as evidenced by the redesignation of all adult hospices from Section 39 to Section 38 status. This change was explicitly intended to secure sustainability and remove reliance on fundraising for core payroll and operational costs.

International evidence shows that children's hospice care is a cost-effective investment that improves patient outcomes while reducing demand on more expensive acute services. Predictable and sustainable funding enables effective service planning, prevents unnecessary hospital admissions, supports earlier discharge, and ensures hospital resources are used where they are needed most.

Despite this, LauraLynn remains structurally underfunded. While adult hospices now receive full State funding as Section 38 organisations, LauraLynn receives just 27% of its core costs through statutory funding.

This disparity creates a significant gap between the cost of delivering a national specialist service and the funding available to sustain it, with direct implications for service continuity, workforce stability, and the capacity to respond to growing demand.

Demand for children's hospice and palliative care has increased significantly in recent years, particularly in community-based provision, in line with national policy objectives to deliver care closer to home and reduce reliance on acute hospitals. LauraLynn has expanded services in response. However, statutory funding has not kept pace with this growth, resulting in a widening gap between available funding and the true cost of delivery.

At current service levels, the total annual operating cost of LauraLynn's hospice service is €11.9 million, of which €3.3 million is provided through Section 39 core funding, leaving a funding gap of €8.6 million.

An uplift in statutory funding for core services has never been more pressing. LauraLynn's dependence on fundraised income to bridge its annual funding gap has been deepening year on year. Amid growing uncertainty in the geopolitical and economic environment, donations and fundraising activity in 2026 is already significantly behind target and an income deficit of €3.6m is being projected this year.

More than ever before, it is essential we achieve a long sought-after fair and sustainable statutory funding footing. At a time when many external factors remain beyond our control, a long-term funding agreement through Section 38 redesignation would provide a clear and sustainable framework, offering much-needed certainty for service planning, workforce retention, and the continued delivery of care to children and families across Ireland.

"Currently yourselves at LauraLynn are the only respite we get where we can leave our child and have time for ourselves."

LauraLynn Mum

Budget 2027 must ensure that:

- LauraLynn's redesignation to Section 38 status is approved without delay and effective from 2027 onwards.
- Full statutory funding of €11.9 million per annum is allocated.

This represents a proportionate, precedent-based solution that aligns children's hospice care with the State's established funding model for adult hospices, while securing the sustainability of an essential national service.

Palliative Care for children is different than for adults:

- Conditions are rare and specific to childhood.
- Palliative phase is much longer, episodic and unpredictable.
- Care embraces the whole family.
- Siblings can be vulnerable.
- Education and play must continue.
- Ideally children with life-limiting conditions should be cared for by paediatric trained staff.

Priority 2: Ring-fence funding for the development of a new Children's Palliative Care Policy

The Programme for Government commitment to develop a new Children's Palliative Care Policy represents a critical opportunity to plan, deliver and sustain services so that children, regardless of where they live, can access the care and supports they need to maximise their quality of life.

Budget 2027 must allocate dedicated funding to maintain momentum in policy development and to ensure meaningful, ongoing participation by children with complex needs and their families. This will require active cross-departmental engagement and sufficient resourcing to deliver an ambitious and timely policy.

"I feel access to LauraLynn for my son has saved me and it gives us hope as a family to do the normal things."

LauraLynn Mum

New national evidence underscores both the scale and urgency of this work. The Evidence for Children's Palliative Care in Ireland (ECHPI) study, the first of its kind in Ireland, suggests that up to 1,500 children may require specialist hospice care at any given time, potentially double previous estimates. This represents a substantial and previously under-recognised level of need that must be reflected in future service planning.

ECHPI also highlights the complexity and intensity of care required. While children with life-limiting conditions account for less than 1% of the population, they represent a disproportionate share of hospital activity, including:

- One fifth of all acute hospital bed days
- 29% of children in intensive care for one month or longer
- 54% of children with hospital stays exceeding three months

These findings point to both unmet need and significant pressure on acute services. They underline the importance of ensuring that future policy is aligned with demand and supported by appropriate capacity, resourcing and service design.

International evidence further demonstrates that early access to palliative care improves outcomes for children and families, while reducing healthcare utilisation, including avoidable hospital admissions, ICU use and length of stay. A key function of the new policy will be to set out how services can be structured to provide timely and equitable access to appropriate care across hospice, home and community settings.

> *"Our community nurses allow us the space to be just parents to our girls."*
> **LauraLynn Mum**

Children with palliative care needs and their families often face complex and interrelated challenges. Experience from service delivery indicates that relatively modest supports, when well designed and coordinated, can significantly improve quality of life. The new policy must therefore adopt a whole-of-government approach, ensuring that all relevant departments are engaged in addressing these needs in a coherent and effective way.

Budget 2027 should provide the resources necessary to support this cross-government approach, enabling the development of a comprehensive, evidence-informed Children's Palliative Care Policy that is capable of responding to current and future need.

Priority 3: Maintain and strengthen the current national funding model

The highly specialised nature of children's hospice and palliative care requires a coordinated national approach to funding and delivery. Such an approach supports consistent standards of care, enables the efficient use of limited specialist resources, and ensures the capacity to respond flexibly to changing and increasingly complex needs.

A national funding model – such as the one currently in place for LauraLynn - is essential to ensure that services are reliable and accessible to all who need them. This model must remain centrally allocated, and must be needs-based and sufficiently resourced, enabling consistent, reliable and equitable access to services across all regions.

As demand continues to grow, maintaining and strengthening this model will be critical to avoiding regional disparities and ensuring that services can be delivered seamlessly across hospice, home and community settings as part of an integrated continuum of care.

Budget 2027 should reinforce the current national funding approach, ensuring stable, predictable, funding aligned with the true level of need. Continuation of the existing national funding structures will support the sustainable delivery of specialist services and ensure equitable access for children and families across the country.

Conclusion

Budget 2027 presents an opportunity to make meaningful progress in how children's hospice care is delivered and supported in Ireland.

The Government's commitment to develop a new Children's Palliative Care Policy provides a clear platform to set out what children's hospice care should be: child- and family-centred, responsive, and accessible across the country. This can now be informed by robust Irish evidence on the scale and complexity of need, alongside a clear funding precedent established through the redesignation of adult hospices to Section 38 status.

Budget 2027 provides a unique window to demonstrate that every child counts. The actions set out in this submission are practical, proportionate, and grounded in both evidence and existing policy direction. Acting on them now will ensure that no time is lost in delivering the care and support that children and their families need, when it matters most.

About LauraLynn

LauraLynn is Ireland's only children's hospice and provides specialist paediatric hospice and palliative care to babies, children and young people with a life-limiting condition and their families, supporting them to live well and enabling them to make the most of every moment when life is short. LauraLynn's vision is that all children and their families can access the care and support they need at every stage of their journey.

About Children's Palliative Care

Children's palliative care is marked by uncertainty. In particular, it is difficult to predict how long a child will survive with a life-limiting condition. Depending on the diagnosis, many children experience several episodes where it appears that they are at end of life; therefore, planning for care is challenging with each episode requiring the same high level of support whether the child dies or not. Despite having a life-limiting condition and often having experienced several potentially end of life episodes when a child dies, parents often report feeling unprepared.

Parents are most often the main providers of care for their child with palliative needs and despite struggling to cope with the diagnosis of a life-limiting condition, home remains the care location of choice for most parents. Most children have their care needs met by their family at home with mothers usually taking on the role of primary carer often with the support of locally based services. Currently, the availability of services can vary depending on the diagnosis and the geographical location of the family home.