



General Election Manifesto

LauraLynn is Ireland's only children's hospice and provides specialised paediatric palliative care services to babies, children and young people with a life-limiting condition, supporting them to live well and to have a good death, and enabling them to make the most of every moment when life is short.

LauraLynn's commitment is to ensure that all children with palliative care needs and their families can access cohesive, responsive, specialist care and support they need at all stages of their journey. Central to this is effective and efficient service planning, development and delivery, underpinned by the following Manifesto Asks.

Manifesto Ask 1

Provide a sustainable level of funding for LauraLynn Children's Hospice

Sustainable funding is vital for long term continuity, planning and meeting complex clinical care needs. Since securing initial stabilising statutory funding in 2021, LauraLynn has expanded its services nationally in response to the requirements of children and families.

Statutory funding followed a commitment in the 2020 Programme for Government, Our Shared Future, to *"invest in end of life care, including the provision of Hospice and end of life care during perinatal, infancy, childhood and adulthood"*.

This followed recommendations in the Slaintecare Report (2017) to provide additional funding for palliative care and specifically *"LauraLynn Hospice, child respite and palliative care services"*.

LauraLynn expects to support a community of care of 675+ children and families by the end of 2024. This represents an 80% increase in families linked to LauraLynn over the 2021-2024 period.

Last year adult hospices in Ireland were redesignated as Section 38 organisations. Speaking about this change, Minister Donnelly said: *"It means that all adult hospices in our country will now be fully state-funded. This is a significant step towards our goal of providing universal access to palliative care"*.

LauraLynn currently receives 27c of statutory funding for every €1 spent on children's hospice care. In Budget 2025, LauraLynn is seeking a total investment of €5.11m (€4.87m + €240k) core funding to achieve a sustainable level of funding. While this represents an increased investment of almost €2.81m, this proposal would see 48c of statutory funding for every €1 spent on children's hospice care. This level of funding would make LauraLynn's work sustainable and ensure that the organisation can provide equitable access to care and support services for children and families with unmet needs into the future.

"By guaranteeing year on year funding they (LauraLynn) can begin planning for the future to provide more and more support and services to sick children and their families"

**Minister for Health
Stephen Donnelly 2020**

As the then Taoiseach, Michael Martin TD noted at the official launch of LauraLynn’s Mallow facility in December 2022;

“It’s wonderful to hear the incredible impact having services available close to home makes and is an important step in our goal to ensure universal access to palliative care”

Manifesto Ask 2

Commit to develop, implement and resource a new national policy on Palliative Care for Children with Life-limiting Conditions

Current work on children’s palliative care is broadly guided by Palliative Care for Children with Life-limiting Conditions in Ireland – A National Policy (2009). Although well received and researched at the time the policy is in desperate need of modernisation. When published, Ireland had yet to open a national children’s hospice, while medical developments and population growth now undermine its conclusions and recommendations.

Conservative estimates suggest that close to 2,000 children with a life limiting condition have palliative care needs in Ireland, of whom more than 740 children are, at any given time, classified as ‘unstable, deteriorating or at end-of-life’, requiring specialist hospice care. However, more recent epidemiological data would suggest the figures could be significantly higher (4,150 children with palliative care needs and 1,579 children are ‘unstable, deteriorating or at end-of-life’). Research also indicates that approximately 370 children die each year with life limiting conditions. Of these deaths, 57% occur in the first year of life. However, the absence of reliable data makes planning and forecasting very challenging.

To ensure that that appropriate care and support is provided to all children with life-limiting conditions and their families a new policy on children’s palliative care is needed. This should be based on a new needs analysis which considers demographical changes; changes in healthcare policy and provision; developments in the treatment of children with life-limiting conditions, and advances in knowledge and learnings in this speciality area. The development of the new policy and implementation plan must give due weight to the voice and influence of children with palliative care needs and their siblings, in line with recent developments in children’s rights and current Government policy.

About LauraLynn

LauraLynn is Ireland’s only children’s hospice and provides specialised paediatric palliative care services to babies, children and young people with a life-limiting condition, supporting them to live well and to have a good death, and enabling them to make the most of every moment when life is short. Services include direct care, symptom management, family support, end of life and bereavement care.

LauraLynn strives to provide choice about when, where, and how families receive children’s hospice care in our purpose-built home from home facility, in hospital, in Leopardstown, or in their home or community.

LauraLynn currently supports a community of care of more than 620 families across Ireland, which is expected to increase to 675+ by the end of 2024. This community of care comprises 364 children availing of the hospice with their family, 189 bereaved families who are therapeutically supported in their first three years of grief and a further 198 bereaved families who remain linked to the service. Families are supported through our multidisciplinary care team, our purpose built eight-bedroom facility in Leopardstown, Dublin 18 and a network of Hospice in the Community Teams based in Dublin, Mallow and Ballinasloe.

“Without LauraLynn I wouldn’t be able to keep caring for my son at home. It is a magical place where he can go and do fun things while having his needs met. I can have a break and breathe.”

LauraLynn Mum

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