



Equitable and timely access to specialist hospice and palliative care services for children with life-limiting conditions has been an under-recognised children's health issue in Ireland and requires action in Budget 2021.

LauraLynn believes a healthcare system wide-approach, with targeted investment and enhanced collaboration would deliver significant improvements in the quality of the lives and deaths of these children and their families.

For Budget 2021 LauraLynn Children's Hospice is calling on the government to:

- 1 Provide **€2.04m** (48%) operational funding for the provision of LauraLynn's specialist hospice and palliative care services, bringing it in line with funding of UK children's hospice (CHAS).
- 2 Provide **€165k** to fund 4 new Paediatric Nurses to facilitate the delivery of LauraLynn's full range of specialist hospice care within the Leinster region.
- 3 Commit to a multi-annual funding approach to LauraLynn Children's Hospice that is equitable with Adult Hospice funding (i.e. 72% operational funding on average) by Budget 2023.

LauraLynn contributes to the discipline of children's palliative care, increasing system capability and capacity, incl;

- **Funding** 2 x Clinical Nurse Specialist posts in CHI Temple Street & CHI Crumlin (in 2021).
- **Supporting** academic specialism (e.g. 0.5 Consultant Paediatrician).
- **Fostering** therapeutic specialism through cross-service practice initiatives (e.g. shared pharmacy post with CHI Crumlin).
- **Providing** tailored Clinical Education, Peer Learning and Student Placements (450 opportunities pa.).

LauraLynn's funding model is unsustainable:

- The Hospice Service receives **NO direct statutory funding**.
- It will cost approximately **€4.3million*** to operate LauraLynn's Hospice Service in 2020.
- Approximately **86% operational funding comes from fundraised income**.
- Approximately **€714k (net) indirect benefit**, in respect of crossover posts due to an existing Section 38 SLA with The Children Sunshine Home Disability Service.
- **59 WTE staff** are employed in providing hospice care, with a further 12 WTE staff working to generate income.

*Excludes the cost of generating funds.

Despite the significant and pressing needs of children with life-limiting conditions and their families, the area of children's palliative and hospice care lags significantly behind the curve in children's health and Irish healthcare in general. This is largely due to historic under-funding of the discipline across hospitals, children's hospice and community-based services.

Most notably, there is a lack of appropriate community-based respite (in and out of home) and inter-disciplinary family supports aimed at sustaining children in their own homes/communities.

LauraLynn recognises the advances made in progressing the National Development Committee recommendations (e.g. appointing an additional CPC Consultant and additional CNC nurses) and welcomes [The Slaintecare Report](#) recommendations for additional funding of palliative care, including funding for LauraLynn Hospice, children's respite and palliative care services (see pages 64 & 182).

Background Information



LauraLynn
IRELAND'S CHILDREN'S HOSPICE

The Facts

- 3,840 children in Ireland are living with a life-limiting condition (LLC). Of these:
 - approximately 50%, or 1,920 children, have palliative care needs;
 - up to 19% (724 children) are medically unstable, deteriorating or at end-of-life; and
 - approximately 350 children die each year.
- More than 30,000 parents, carers, brothers, sisters, relatives and friends are impacted by caring for a child with a LLC.
- The UK has 53 children's hospice services including **more than 40 children's hospices**.

Making an impact

Since its opening in September 2011 more than **450 children** with life limiting conditions and their families have availed of LauraLynn Hospice care.

The hospice continues to grow. Between 2016-2019 there was a **28% increase** in the number of families using the service annually.

In 2019:

- **55 new referrals** were accepted to the hospice, meaning more than **374 families**, from **25 counties** availed of specialist care. This comprised
 - 209 children and families receiving Direct Care, Symptom Management, Family Support and End-of-Life care;
 - 165 families availing of Bereavement Care, Support and Activities.
- More than **1,560** short break, respite, crisis care and symptom management **bed nights** were facilitated.
- **529 home visits** were carried out by LauraLynn's community team, while 19 families received additional joint Music & Occupational Therapy sessions in their family home.
- **52 children** who accessed LauraLynn services died in 2018.

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 LLCs should be cared for by paediatric trained staff.

[^] The Palliative Care for Children with Life-limiting Conditions in Ireland – A National Policy

About LauraLynn Children's Hospice

LauraLynn is the only children's hospice in the Republic of Ireland, providing palliative care to children with life-limiting conditions (aged 0-17 years) and their families from all across Ireland.

The service focuses on enhancing quality of life, which includes the physical comfort and wellbeing, as well as the emotional, social and spiritual aspects of care of the child and family; supporting them from the point of diagnosis to end of life, and throughout bereavement, with a range of nursing, practical, emotional and medical care. Services incl:

- Short Breaks (Respite).
- Symptom Management.
- Family Support.
- End-of-Life Care.
- Bereavement Support.

Care can be availed of in our hospice in Dublin, at hospital, in the community, or in the family home, depending on the location, medical needs and preference of the child and family.

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 and often children experience several episodes where it appears that they are at end-of-life. Parents are most often the main providers of care and, despite struggling to cope with the diagnosis and ongoing care of their child, home remains the care location of choice for most. With limited primary care services currently available in Ireland, parents can struggle to access the care that their child requires.

Respite, either in or away from the home, is viewed as a key component of children's palliative care, enabling parents to cope with the everyday routine of caring for their sick child and allowing them time to undertake everyday tasks such as shopping or importantly spending time with their other children. In line with current policy, respite care should be located as close to home as possible.