



Presentation to the Joint Oireachtas Committee on Health and Children

Public Hearings on End of Life Care

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Introduction:

Lauralynn is a voluntary organisation dedicated to the development of a comprehensive service for children with life-limiting conditions and their families who require palliative care. Built on the site of the Children's Sunshine Home, Lauralynn House is Ireland's only purpose built hospice for children. Lauralynn House opened in September 2011 and is an eight-bedded unit providing respite, transitional, crisis and end of life care to children with life-limiting conditions. Whilst the majority of children using our services are from Dublin and the surrounding counties we have recently seen an increase in the number of children from across Ireland who avail of our services.

Palliative and End-of-life care for children:

When considering the question of what needs to happen in order for children to die well in Ireland, it is important to remember that uncertainty is an integral part of children's palliative care and that in childhood conditions in particular, dying is not a linear process.

End of life care is an integral part of palliative care for children however rather than focussing on end of life, the focus in children's palliative care is on enabling children to live well until they die. Children's¹ palliative care is a small, highly specialised area of healthcare that has become increasingly of interest to healthcare professionals. It has been defined as an active and total approach to care embracing physical, emotional, social and spiritual elements. It focuses on enhancement of the quality of life for the child and support for the family and includes management of distressing symptoms, provision of respite and care through death and bereavement (*ACT 2009*). **A life-limiting condition is defined as any illness for which there is no reasonable hope of cure** and from which the child is unlikely to survive beyond early adulthood (*DOHC 2010*)².

¹ The term children encompasses infants, children, adolescents and young adults

² In this paper the term "life-limiting" refers to life-limiting, life-threatening and life-shortening conditions.

A recent study from the USA found that children who received palliative care were less likely to undergo invasive procedures prior to death and were less likely to die in Intensive Care. The authors also found that diagnosis was a factor in the receipt of palliative care with children with neurological disabilities the most likely recipients (*Keele et al 2013*). Technological advances mean that many children who would have previously died are living longer.

Children’s palliative care differs significantly from adult palliative care and therefore professionals and care-givers supporting children require specific training and expertise to deal with their unique needs. There is a notable overlap between the needs of children requiring palliative care and those with disabilities and other complex care needs. Children continue to develop physically, emotionally and cognitively throughout their illness thus their care needs and palliative care needs change over time.

(LauraLynn & Irish Hospice Foundation 2013).

Currently, the provision of services to children with life-limiting condition depends on diagnosis and the geographical location of the family home. As a result of limited primary care services in Ireland parents often struggle to access the care that their child requires. Comparisons with children’s palliative care services in the UK are often drawn however; it is noteworthy that in the UK there are paediatric nurses working as part of the community team. Parents require support to enable them to provide care for their sick child whilst often also caring for their other children. In particular, services such as respite (in-home and out-of the home) are valued by parents and **respite is viewed as a key component of children’s palliative care.**

Identifying the children who need palliative care:

As **the range of conditions that are potentially life-limiting in children is vast**, identifying which children may need palliative care services can be challenging. Internationally, four groups of conditions have been identified as encompassing those who are most likely to require palliative care services, however, many but not all children with these conditions will require palliative care (Table 1) (ACT 2009). Some life-limiting conditions are inherited and as a result of this some parents may have to face dealing with a life-limiting condition in more than one of their children.

Table 1 - ACT groups of life-limiting conditions (ACT 2009)	
1.	Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails. Children in long term remission or following successful curative treatment are not included. Examples: <i>cancer, irreversible organ failures of heart, liver, kidney.</i>

II.	Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Example: <i>cystic fibrosis</i> .
III.	Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples: <i>Battens Disease, muscular dystrophy, mucopolysaccharodosis</i> .
IV.	Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Examples: <i>severe cerebral palsy; multiple disabilities, such as follow brain or spinal cord injury</i> .

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 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 level of support whether the child dies or not** (Figure 1).

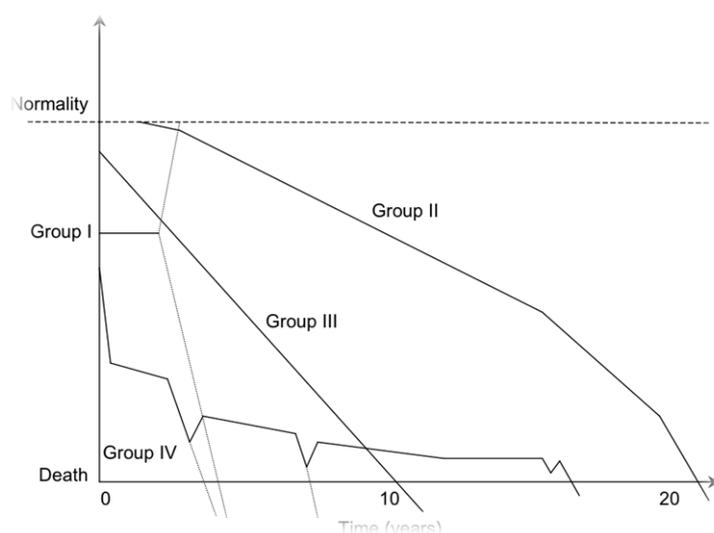


Figure 1 – The trajectory of life-limiting conditions in children by group

The course of a life-limiting condition in a child is often unpredictable. Some children require palliative care for a few days or months while others may live into adulthood and require palliative care (including respite care) over several or sometimes many years. Many children with life-limiting conditions have long periods when they are relatively stable and do not need specialist palliative care but still require other palliative support such as respite.

Childhood deaths in Ireland:

In Ireland the most recent figures available show that approximately 423 children die each year and of these approximately 322 are from life-limiting conditions (Table 2). The **majority**

of deaths occur in the first year of life. Of all childhood deaths in Ireland, 57% occur in infant (<1 year age) and 32% in the first week of life. Congenital anomalies are a leading cause of death in this age group. These children all have palliative care needs.

Table 2 -Mortality data for children under 18 years in Ireland 2002-2010 (CSO 2012)		
Year	Number of deaths	Number of deaths from life-limiting conditions
2005	417	292
2006	421	321
2007	413	306
2008	462	347
2009	403	316
2010	423	348
TOTAL	2,539	1,930
Average annual number of childhood deaths	423	322

As children with life-limiting conditions may be close to death many times and this presents a **compelling argument why childhood deaths are a poor indicator of the need for end of life and palliative care.** Determining the number of children living with a life-limiting condition is difficult. In 2005 it was estimated (based on Irish and international data), that there are approximately 1400 children living with a life-limiting condition in Ireland (*DOHC 2005*). This figure forms the basis for all calculations of children’s palliative care service requirements including respite (figure 2).

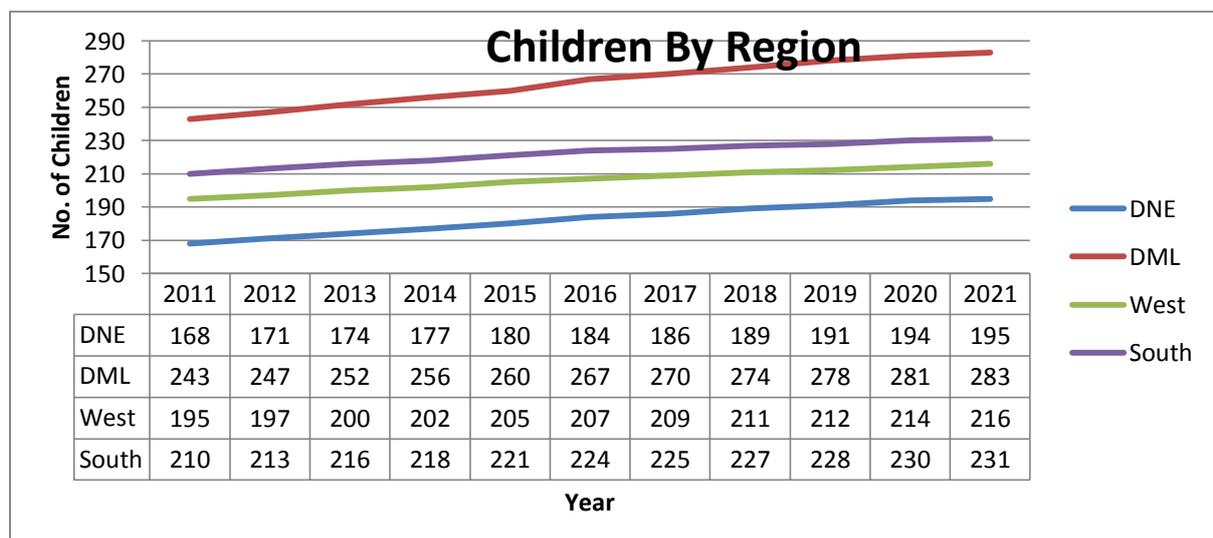


Figure 2. Projected no. children with active palliative care requirement in all HSE areas

An important consideration is the findings of recent research from the UK however, indicates that these figures are likely to be severely underestimated with true figures likely to be at least three times higher at 32 per 10,000 children resulting in a **revised estimate of approximately 4,000 children living in Ireland with a life-limiting condition** (Fraser et al 2012). It is important to plan for services based on the number of children living with a potentially life threatening condition rather than basing calculations on the number of children who die.

Collaborative working in children’s palliative care:

In order to provide comprehensive palliative care services for children and their families collaborative working between the whole healthcare system is required and should include voluntary and statutory providers of care. There are currently a number of key stakeholders providing support to children and their families (Figure 3). Evidence suggests that children may spend up to 5 times longer under the care of a palliative care teams than adults (Hain 2013). This has consequences for all stakeholders and ideally requires a collaborative approach to providing care that meets the needs of the child and family.



Figure 3. Key stakeholders in children’s palliative care in Ireland

Providing palliative care services for children:

All health care professionals working with children and their families should be familiar with the principles of a palliative care approach and be able to recognise their palliative care needs (level 1). All physicians and nurses involved in caring for children should be trained in basic approaches to symptom management and in clear compassionate communication with children and families (level 2). There should be recognition of when referral to a specialist children's palliative care service is necessary (level 3). It is noteworthy that not all children with life-limiting conditions will need referral to a specialist service and many can be managed by their primary team. However, all three levels of children's palliative care should be available to all children with a life-limiting condition in all care settings as necessary.

Policy underpinning children's palliative care:

There have been several key documents published in Ireland in recent years relating to palliative care for children. The **National Advisory Committee Report (2001)** focused on the provision of palliative care for adults, however the Committee specifically highlighted that children's palliative care was different to adult palliative care and recommended that local needs assessments were undertaken on the development of children's palliative care. This recommendation was the catalyst for the **Palliative Care Needs Assessment for Children (2005)**. This was a national needs assessment which identified issues which needed to be addressed in order to provide appropriate palliative care services for children in Ireland. Findings of this research indicated a need for:

- Equity in service provision
- Better coordination of and access to services
- Homecare and community services to be developed
- Accurate data collection on prevalence and mortality
- A "key worker" for each family to improve coordination and access to services
- Education and training of health care professionals
- Ready access to locally based respite
- Improved hospital facilities particularly for dying children and their families
- Planning of the development of services
- Specific needs of adolescents to be recognized and considered
- A broader range of bereavement supports to be available

A national policy was developed by the Department of Health and Children, **Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy (2010)**. Published with the aim of addressing the issues raised in the needs assessment this policy now provides a blueprint for the development of children's palliative care services. Several of the key recommendations have been implemented including: the establishment of the National Development Committee on Children's Palliative Care; the appointment of the first Consultant Paediatrician with a Special Interest in Palliative Care and eight regional outreach

nurses. These achievements have relied heavily on the voluntary sector for funding. Several key recommendations that remain outstanding include:

- **The development of a range of respite services (including in-patient hospice beds, community)**
- **The development of Hospice-at-home teams**
 - To include Multidisciplinary team access
 - End-of-life care
- **The development of bereavement support**
- The collection of accurate data
- **Education and training of healthcare staff**
- **Collaborative working between statutory and voluntary agencies**

Government policy is clear on the development of services for children with life-limiting conditions and their families and by all stakeholders adhering to this policy it is possible to develop comprehensive and cohesive children's palliative care services in Ireland.

Current situation at LauraLynn House

There is clear evidence to support the role of children's hospices in the provision of palliative and end of life care. Evidence from the United Kingdom and Canada suggests that not only do children with life-limiting conditions benefit from hospice care but their parents and siblings also find admission to a children's hospice to be beneficial (Eaton 2008; Davies et al. 2004).

LauraLynn Children's Hospice aims to provide holistic care to children with life-limiting conditions and their families through the provision of comprehensive palliative care services. Our primary aim is to allow children to live well until they die. The philosophy of the hospice is to promote the best possible quality of life and care for every child with a life-limiting condition and their family. Giving families real choice has been key to this approach; a choice of place of care; a choice of place of death; a choice of emotional and bereavement support; and putting the child and family at the centre of decision making, to produce a care plan that is right for them. Our vision is that high quality palliative care will be available to all who may need it, in all care settings and in line with national policy and best practice.

In the two years since opening (September 2011 until August 2013) we have provided care to 198 children and their families. The majority of these children remain under our care where we provide support such as respite; during this time we have cared for 35 children at the end of life. The majority of the children under our care are from Dublin and the surrounding counties. We accept referrals nationwide and have had admissions from all over Ireland including Kerry and Donegal.

At LauraLynn we recognise the essential role of education and research in progressing our small but highly specialized field of healthcare. In 2012 we established a **Clinical Education and Research department** dedicated specifically to the provision of responsive programmes, seminars and workshops for professionals, carers and parents involved in the care of children with life –limiting conditions. This new department is underpinned by the strategic objectives of LauraLynn Ireland’s Children’s Hospice to care for children with life-limiting conditions and palliative care needs. The department aims to educate, train and empower professional colleagues who deliver care to meet the very unique needs of children with life-limiting and terminal conditions. These include colleagues in tertiary care, primary care and adult palliative care services.

As children’s palliative care is such a new and evolving specialty it is essential that services can provide evidence of what they are providing and how or if this has made a difference to children with life-limiting conditions and their families. Internationally, there is very limited evidence to either support or refute the role of children’s palliative care in improving support and care to families. Evidence is required to demonstrate the value and the need to show how hospice is able to make a difference

Funding:

Unlike adult voluntary hospices who receive 69% of their revenue funding and 19% of their capital funding from the state, 100% funding for LauraLynn Children’s Hospice has been achieved through fundraising activities including the capital costs of €5.5 million and annual revenue costs of €2.4 million.

Conclusions:

1. LauraLynn is Ireland’s only children’s hospice. Providing care to children with life-limiting conditions and their families and supporting them in caring for their child in their location of choice be that home or as an in-patient. LauraLynn receives no state funding.
2. End of life care is only one part of palliative care. The focus of care is to help children live well until they die rather than focussing on the last hours and days of life. Depending on diagnosis children may use palliative care for many months and years.
3. Children’s palliative care is different to palliative care for adults.
4. All plans for the future development of LauraLynn Services are in line with national policy and include the development of LauraLynn at home.
5. Collaboration between all stakeholders involved in caring for children with life-limiting conditions will provide families with the best quality of care.
6. Formal links between the Consultant Paediatrician with a special Interest in Children’s Palliative Care and LauraLynn are required.

7. A major challenge nationally in children's palliative care is a lack of suitably trained and qualified staff to provide care to children and their families at the end of life.

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