



Presentation to the Joint Oireachtas Committee on Health and Children

Public Hearings on End of Life Care

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I would like to thank the Chairman and members of the committee for this opportunity to speak today on end of life care for children from the perspective of LauraLynn Children's Hospice. End of life care is one aspect of children's palliative care. In children's palliative care the focus is on enabling children to live well until they die. I would respectfully urge the committee to refocus on the wider concept of palliative care rather than specifically on end of life care. I am newly appointed as Head of Strategic Development at LauraLynn Ireland's Children's Hospice. Prior to taking up this post I have spent the last three years undertaking research with the parents of children with life-limiting conditions requiring palliative care. Meeting with and listening to parents it is clear to me that the services currently provided do not entirely meet the needs of the child with a life-limiting condition and their family.

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. As children with life-limiting conditions may be close to death many times, this presents a compelling argument as to why childhood deaths are a poor indicator of the need for end of life and palliative care. Furthermore 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.

For children with palliative care needs, parents are most often the main providers of care and despite struggling to cope with the diagnosis of a life-limiting condition; home remains the care location of choice for most parents. In children's palliative care, the child and family are viewed as the unit of care. Ideally support for children with palliative care needs should begin at the time of diagnosis and for many children with life-limiting conditions this can be at the time of birth. 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 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. Respite (either in the home or away from the home in units such as LauraLynn) 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.

LauraLynn is the only purpose built children's hospice in Ireland providing respite, transitional and end of life care for children with life-limiting conditions and their families. Using a multidisciplinary approach, care is tailored to meet the individual needs of the child and family. Unlike adult voluntary hospices who receive 69% of their revenue funding and 19% of their capital funding from the state, all funding for LauraLynn Children's Hospice has been achieved 100% through fundraising activities including the capital costs of €5.5 million and annual revenue costs of €2.4 million.

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. If people, including children wish to die at home there needs to be investment in the provision of community services in order to facilitate this. Palliative care services are vital but so too are community based staff to provide care and support to families.

At LauraLynn we recognise the essential role of education and research in progressing our small but highly specialised 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. We provide a range of courses and study days aimed at developing staff from our hospice and the wider healthcare community.

For children with life-limiting conditions the preferred place of care and ultimately death is the family home. The provision of support such as respite and the break that this provides enables families to continue caring for their child. Whilst many parents wish their child to die at home this is not always possible and in such cases families may choose hospital or hospice as their desired place of care at end of life.

Ultimately children's palliative care needs are best met through an integrated coordinated approach involving all stakeholders including hospice, hospital-based teams, voluntary organisations such as Jack and Jill, community and primary care teams and specialist palliative care where necessary.

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. LauraLynn Children's Hospice aims to provide holistic care to children with life-limiting conditions and their families. 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.

Key points to consider:

1. End of life care is only one component of palliative care. Care should focus on helping children to live well until they die.
2. All of LauraLynn's plans for future development are in line with national policy and are responsive to parent need. This includes the development of LauraLynn@home (hospice at home).
3. LauraLynn would like formal links with the Consultant Paediatrician with a Special Interest in Palliative Care.
4. LauraLynn receives no state funding.

Heartfelt thanks again to the Chairman and members of the committee for this opportunity to share LauraLynn Children's Hospice's perspective on children and their needs and what needs to happen to ensure children live well until they die.