



Pre-Budget Submission

Priorities for Children's Palliative Care

2019-2021

***Identified by the main charities in Children's Palliative Care and leading clinicians & academics in Paediatric Palliative Care including:**

- Sharon Foley, CEO, Irish Hospice Foundation
- Dr. Mary Devins, Consultant Paediatrician with a special interest in Paediatric Palliative Medicine
- Dr. Maeve O'Reilly & Dr. Marie Twomey, Consultants in Palliative Medicine, Our Lady's Children's Hospital Crumlin and St. Luke's Hospital
- Claire Quinn, Lecturer, Programme Director MSc/PGD Health Sciences (Children's Palliative/Complex Care), NUIG
- Carmel Doyle, CEO (Interim), The Jack and Jill Foundation
- Orla O'Brien, CEO, LauraLynn, Ireland's Children's Hospice (since May 2018)

Introduction

In Ireland:

- Approximately 370 children die each year with life-limiting conditions (LLC).
- Of these deaths, 57% occur in the first year of life.
- Estimates indicate there are nearly 4000 children with LLC in Ireland today¹.
- These children have exceptional and unique healthcare requirements and it is estimated that at any one time 50%² (approx. 1,960) of these children will require active paediatric palliative care.

In 2010, based on a comprehensive needs assessment completed in 2005, the Department of Health published *Palliative Care for Children with Life-limiting Conditions – A National Policy (2010)*. This policy was a universally agreed vision for improving children's palliative care in Ireland.

The first phase of implementation included:

- The provision of education and training for staff
- The appointment of a Consultant Paediatrician with special interest in Paediatric Palliative Medicine (Consultant PPPM)
- The establishment of a national network of (initially) eight clinical nurse coordinators (CNCs) based in key locations around Ireland.

These priorities were implemented over the next 3-5 years under a partnership agreement between the HSE and the Irish Hospice Foundation, alongside developments from the HSE and other charities/agencies working in the area of children's palliative care.

The policy also acknowledged the significant role of the voluntary sector in responding to the healthcare needs of children with LLCs and recommended their ongoing involvement in the planning and delivery of specialist palliative care services be encouraged and facilitated. The report advised that the HSE and voluntary agencies should develop closer working relationships around caring for children with LLCs and that Service Level Arrangements should form the basis of future working relationships between the HSE and voluntary service providers.

There has been much progress since the publication of the national policy, and there are many reasons to be proud of these achievements. We now have an established Children's Palliative Care Programme (CPCP), but there are further unmet needs. The service was evaluated in 2016 and the report is publically available.³

¹ <https://www.imo.ie/news-media/publications/March-2015-Irish-Medical-Journal.pdf>. Accessed Oct 2017.

² Fraser LK, Miller, M Hain, R, Normand, P., Aldridge, J., McKinney, P., Parslow, R. (2002) Rising National Prevalence of life-Limiting Conditions in Children in England. *Pediatrics* 2012;129:E923-E929.

³ <http://hospicefoundation.ie/wp-content/uploads/2016/11/Evaluation-of-the-Childrens-Palliative-Care-Programme-2016.pdf>

A key recommendation from this evaluation was as follows:

“The findings of this evaluation should be discussed by the DoH and HSE and used as evidence for the development of priorities for policy and service development. These priorities should reflect identified deficits including bereavement services for parents who have suffered the loss of a child; respite care (at home and out-of-home) for parents caring for a child with a life-limiting condition/complex care needs; proper provision for end-of-life care; access to appropriate out-of-hours care; the transition from children’s to adult services for young people with a life-limiting conditions.”

The report also reaffirmed the vital role of the voluntary sector service providers, acknowledging that the CPCP forms only part of the full spectrum of children’s palliative care services which are provided in hospitals, the community and through voluntary and charitable organisations.

The Sláintecare Report (2017) recommends Universal Palliative Care with significant investment in the first five years of the plan, including children’s palliative service and service providers.

In 2018, a group comprising of those charities supporting and working in the area of specialist children’s palliative care, in partnership with lead medical clinicians providing children’s palliative care and NUI Galway (*providing level 9 education*) met with the Minister for Health to discuss the next stages in children’s palliative care. This group continues to advocate for investment and support for children’s palliative care.

The following are the priorities highlighted by this group for consideration in 2019 Estimates process. These priorities have been derived from recommendations for service development identified in the recently published National Model of Paediatric Care (*Chapter 39 outlines needs for paediatric palliative care*)⁴. They also include further recommendations arising from the National Evaluation report completed in 2016.

Short term priorities (1 to 4 years)

○ **General**

The HSE should ensure a formal process of partnership-working, involving key statutory and voluntary sector services, is in place in order to identify and implement service development priorities.

To enable this:

- **The National Development Committee (NDC) should be re-established** and supported throughout 2019. Membership of the NDC is guided by national policy recommendations. At present an interim advisory group is in place
- **Employment of the National Programme Manager** (funded initially by Irish Hospice Foundation and Laura Lynn) should be prioritised by the HSE.

⁴ <https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/paediatric-palliative-care.pdf>

- **The HSE** should implement a Service Level Arrangement approach and appropriate funding agreements with voluntary sector service providers caring for children with life-limiting conditions.

○ **Priorities for Acute Hospital Services requirements for Paediatric Palliative Care**

(Eventually to be contained within the National Children's Hospital)

The National Evaluation report clearly highlighted the benefits and effectiveness of the Consultant-led Specialist Palliative care team at Our Lady's Children's Hospital (OLCH) Crumlin working with the Clinical Nurse Coordinators (CNC). The team is under resourced yet consultants and CNS are supporting paediatric teams and CNCs all over the country. This national centre will serve to support paediatric palliative care nationally when the new children's hospital is in operation.

Priorities are as follows:

- **Three paediatricians with a special interest in Paediatric Palliative Medicine** who work *exclusively* in children's palliative care are required. One whole-time equivalent (WTE) is currently in post in OLCH Crumlin and the Irish Hospice Foundation has funded a second post in CUH Temple Street, with a commitment for long term funding from the Department of Health. **One further consultant will be required.**
- **Two additional CNS are required**, one for CUH Temple Street and one for OLCH Crumlin.
- **A national lead neonatal nurse (CNS Grade) for Palliative Care** is required, to be based in maternity hospital settings.
- **Outpatient clinics** which would allow patients to attend for multiple disciplines should be developed.
- Each Hospital Group/Community Health Organisation should be encouraged to examine their provision of paediatric palliative care with a view to strengthening the paediatric nursing resources/expertise within the Home Care teams who provide vital end of life care to children in the community. The potential role of the CNC, ADON and Champion Consultants should be maximised in order to improve service integration and the overall development of children's palliative care.
- The new National Co-ordinator should support the Children's Palliative Care Clinical Governance and Development Network and examine the findings of this report with a view to developing a series of educational, governance and operational recommendations to guide the continued development and support of the CNC service.
- The HSE should ensure the continued funding of the Level A and Level B training courses on caring for children with life-limiting conditions provided by the Centre of Children's Nurse Education in OLCH Crumlin, with a commitment to support level 9 training in NUI, Galway.

○ **Priorities for Community Outreach**

- Further resources are required for the provision of the Children Nurse Co-ordinator outreach service. There are currently 10 established CNCs. The HSE estimate an additional 10 nurses would be required on a phased basis over next 5 years.
- The link between paediatric and adult based palliative care services will be required to continue in the future and it is therefore suggested that the clinical governance of this service provision should be supported and further developed.
- Models of respite in home/out of home for families caring for children with life-limiting illness in critical stages of illness (deterioration and end of life) need to be developed and supported, building on those developed by the one-off pilot (2014-15) HSE CHO 3 (MidWest) and LauraLynn Children's Hospice, and ongoing work of The Jack & Jill Children's Foundation and working in partnership with disability services.
- Bereavement care for parents and families bereaved of a child should be developed in the context of agreed national standards (such as pyramid of support) and existing networks (such as the Irish Childhood Bereavement Network) and other service providers and agencies.

Medium term (5 to 7 years)

- A fully resourced specialist paediatric palliative care team is required for the new National Children's Hospital (**National Centre of Excellence in Paediatric Palliative Care in the National Children's Hospital**), see 'New Children's Hospital' section below.
- Appointment of general paediatricians with a special interest in Paediatric Palliative Medicine in regional units (Cork, Galway, Limerick).
- Further expansion of the CNC outreach service for children with life limiting conditions, as required.
- Develop perinatal and neonatal palliative care support services.
- Development of a national database of children with life limiting conditions, either current or retrospective.
- Funding for respite for in-home/ out-of-home for families caring for a children with life limiting illness in critical stages of illness (deterioration and end of life).
- Paediatric palliative care to be recognised as sub-speciality of paediatrics.

Long term (7+ years)

- Maintain and build on the objectives outlined for the medium term.
- Funding for paediatric palliative care services to be provided by the State.

Table 1: From National Model for Paediatric Care - Staffing required for new children's hospital (updated June 2018) for Children's Palliative Care

Staff Category	Current (WTE)	Proposed (WTE)
Consultant	2.2 ⁵	3.2
SpR Paediatrics	0	1
SpR Palliative Medicine	0.2	0.2
Registrar Paediatrics	0	1
SHO Paediatrics	0	1
Clinical nurse specialist	1.5	4.5
Psychologist	0	1
Social Worker	0	1
Administrative support	0.11	1

Access required from: dietetics, physiotherapy, occupational therapy, play specialists
Support required from bereavement coordinator

Further Information

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⁵ A second consultant is appointed to Temple St from Oct 2018 onwards. The IHF have agreed to fund the first year of the post after which it will be funded by the HSE/Dept of Health.

