



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

# Children's Palliative Care:

*From policy to practice 2010–2015*

Implementing Palliative Care for Children  
with Life-limiting Conditions in Ireland  
– A National Policy (2009)

# INTRODUCTION

**The National Development Committee for Children’s Palliative Care (NDC) was established by the Health Service Executive in in 2010. The NDC oversees the implementation of the recommendations contained within the national policy for children’s palliative care through collaborative action. This document highlights the achievements, challenges and future plans for the development of children’s palliative care services in Ireland.**



## Background to the National Development Committee for Children’s Palliative Care

The 2009 seminal policy document recommended the establishment of the National Development Committee (NDC) for Children’s Palliative Care. The committee was formed by the Health Service Executive (HSE) in 2010 and its main purpose is two-fold:

- to oversee the implementation of national policy recommendations
- to demonstrate leadership by working strategically to improve children’s palliative care services.

The NDC is a collaborative committee. The chair is the HSE National Lead for Palliative Care. The co-chair role is rotated and the current co-chair is the CEO of LauraLynn Children’s Hospice. A broad range of statutory and voluntary organisations as well as parents are represented on the committee.

Members work together to pool resources, knowledge and expertise in order to ensure services are developed in a sustainable manner in accordance with national policy. A detailed report on the work of the committee against the 2009 policy recommendations is available on request. The committee can be contacted for advice and information via the chair, Ms Sheilagh Reaper-Reynolds, HSE National Lead for Palliative Care. [sheilagh.reaper-reynolds@hse.ie](mailto:sheilagh.reaper-reynolds@hse.ie)

### Organisations represented on the National Development Committee

Centre of Children’s Nurse Education

Jack & Jill Children’s Foundation

LauraLynn Children’s Hospice

Our Lady’s Children’s Hospital Crumlin

The Department of Health

The Health Service Executive

- Children’s Outreach Nurse Service
- Disability Services
- Paediatric Services
- Palliative Care
- Primary Care

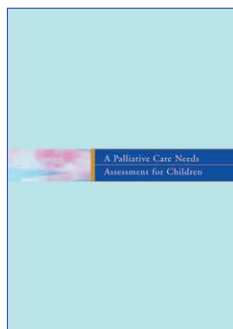
The Irish Association for Palliative Care

The Irish Hospice Foundation

A parent representative is also a member of the NDC

## Chronology of children's palliative care policy in Ireland

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### **Palliative Care Needs Assessment for Children (2005).**

This national needs assessment estimated that there were approximately 1,400 children living with a life-limiting condition in Ireland and that services, where available, for children and their families were often dependent on diagnosis and the geographical location of the family home. The preference for children to be cared for at home was recognised. The report also highlighted the lack of coordinated care as an issue for families. Parents also stressed the need for a key worker and the provision of suitable respite and home care as a priority.

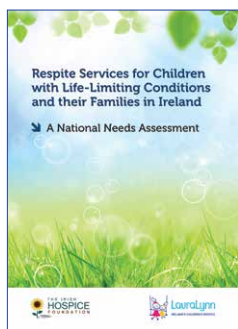
[!\[\]\(23d9fc146e83b5c3013cfa32c784f8d5\_img.jpg\) Download a copy](#)



### **Palliative Care for Children with Life-limiting Conditions in Ireland - A National Policy (2009).**

This policy set out the vision and framework for the development of services for children with a life-limiting condition and their families. It is divided into three sections. The first section defines and describes palliative care for children with life-limiting conditions and draws on national and international developments in this small and highly specialised field of healthcare. The second section describes services as they were provided at the time. The third section gives clear direction for the future development of palliative care for children.

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### **Respite Services for Children with Life-limiting Conditions and their Families in Ireland - A National Needs Assessment (2013).**

This report provides a national overview of the provision of, and future need for, respite care for children with life-limiting conditions. It seeks to provide a clear overview of national requirements for respite as part of a palliative care service for children in Ireland. Respite care is an essential component of children's palliative care and yet further work is required to identify where children are currently receiving care and if this meets the needs and expectations of parents and the child. Some groups of children with palliative care needs receive respite care through disability services.

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## Key achievements

- Establishment of the National Development Committee for Children's Palliative Care which reports to the HSE at National Director level.
- Appointment of Ireland's first Paediatric Consultant with a Special Interest in Palliative Care.
- Appointment of eight Children's Outreach Nurses for Life-Limiting Conditions based in acute hospital paediatric units across the country, with a further two posts approved.
- Appointment of a part-time National Development Coordinator for Children's Palliative Care. A collaborative partnership will shortly appoint a full-time coordinator for a three year period.
- Development of a comprehensive Education and Governance Framework to direct and support the work of the children's outreach nurses.
- A national Clinical Governance and Development Network to oversee the development of referral guidelines, care pathways and protocols has been established.
- Development of a range of education and training programmes for healthcare professionals, aligned with the national Palliative Care Competence Framework.
- Completion of a nationwide needs assessment of respite for children with life-limiting conditions requiring palliative care.
- Commissioning of a detailed external evaluation of the children's palliative care programme.
- Development of an all-Ireland integrated children's palliative care [website](#).
- Development of research and evaluation in children's palliative care.

## Working in partnership for children's palliative care

The development of children's palliative care in Ireland is underpinned by a collaborate approach between statutory agencies and voluntary organisations.

The HSE would like to acknowledge the particular contribution of the Irish hospice Foundation who generously funded up to 85% of the start-up costs associated with some of the main developments in children's palliative care; such as the funding of consultant and nursing posts as well as the development of education programmes and the co-funding of national reports.



**Dr Mary Devins**  
Ireland's first Paediatric  
Consultant with a Special  
Interest in Palliative Care

## Caring for children in their home

Work continues in the community to enhance and extend the care delivered to children with life-limiting conditions and their families:

- The **HSE Mid-West** in conjunction with **Milford Care Centre** carried out a pilot project to develop a model of care for the delivery of a Hospice at Home service for children with Life Limiting Conditions in the HSE Mid-West area. The key outcomes from the pilot project are: the establishment of referral criteria, development of 'the Child's Journey' model of care and recommendations for service development.
- **LauraLynn Children's Hospice** developed and implemented a pilot hospice in the home programme in 2014; LauraLynn@Home. An evaluation of the pilot was conducted by UCD and the report published in 2015 demonstrates the benefits of an in-home programme. The LauraLynn@Home service continues to operate in 11 counties in the eastern region.
- **The Jack & Jill Children's Foundation** was founded in 1997 to provide support and home respite for children with severe neurological conditions and all children requiring end of life care up to the age of four years old. The model of care strives to empower families to care for their child at home, utilising the expertise of a Specialist Children's Liaison Nurse and a respite support service that is child and family centred and family led. The Jack & Jill Children's Foundation provides a nationwide service led by a highly skilled and experienced nursing team who have supported over 2,000 families to date. There is no waiting list, and Jack & Jill operates 365 days a year.

## Evaluating key developments in children's palliative care

Following the publication of Ireland's first-ever national policy for children's palliative care in 2009, three new services were introduced by the HSE in 2011.

- The appointment of eight Children's Outreach Nurses for Life-Limiting Conditions across Ireland
- The appointment of Ireland's first Paediatric Consultant with a Special Interest in Palliative Care, based in Our Lady's Children's Hospital, Crumlin (OLCHC)
- An education programme delivered by the Centre for Nurse Education, also at OLCHC.

An evaluation of these services was commissioned by the HSE, Department of Health and the Irish Hospice Foundation. The report of this evaluation study will be available in mid-2016.

Preliminary findings show that whilst there were some initial developmental issues which need to be addressed, there is strong evidence that the programme is well established. The findings also indicate that children's palliative care is gaining acceptance as integral to the provision of paediatric care and is becoming increasingly embedded in

service provision. This endorsement suggests that the current programme of work which includes the Consultant Paediatrician with a Special Interest in Palliative Care service, the Children's Outreach Nurses and the national education programme is making an impact.

The evaluation supports the expansion of children's palliative care services and the further integration between palliative care and other community services. There is a recognised need to develop and facilitate improved communication between service providers and to strengthen quality assurance by ensuring that the correct tools such as guidelines, protocols and pathways are available and implemented across services.

In summary, the report from the evaluation study recommends:

- The appointment of additional children's outreach nurses
- The appointment of an additional consultant
- That services should develop in a way that ensures equitable access for children and families in both rural and urban areas.

## Challenges in children's palliative care service development

### The National Development Committee for Children's Palliative Care has identified a number of challenges in meeting the needs of children and families:

- Utilising recent UK data has resulted in a significant upward revision of the estimated prevalence of children in Ireland with a life-limiting condition. It is estimated that the current number stands at 3,840 children. Approximately 350 children die in Ireland each year due to a life-limiting illness. This has major implications for provision of services to children and their families.
- Access to some services can be dependent on the child's diagnosis and the geographical location of the family home :
  - Consultant community paediatricians are available in some areas but services are limited
  - Although children's outreach nursing services are available in most areas, services are stretched and some geographically remote areas are challenging
  - Home support services are difficult to source as there is a shortage of community based paediatric trained nurses and carers. Caring for a child with a life-limiting condition requires specific skills and experience and there is a lack of nurses and carers with these competencies. In many cases, parents can access funding for the care of their child but may be unable to access staff with the required skills. A comprehensive workforce planning initiative needs to be put in place.
- Respite services are essential both at home and out of home, but are not routinely available to parents. Respite is vital to parents and families often enabling them to continue to provide care for their child at home. There is currently a dearth of suitable respite options to meet the needs of children and their families.
- Quick and easy access to the equipment needed to enable parents to care for their child at home continues to be a challenge. This can vary from very basic appliances to high tech equipment.
- In order to ensure a sustainable workforce in children's palliative care, there is a need to increase investment in education and training. Courses need to be targeted at all levels of palliative care provision.
- Bereavement care and follow-up are an essential component of children's palliative care. The death of a child has an impact that lasts a life-time for the child's family and friends; access to appropriate bereavement support is essential. The establishment of the Irish Childhood Bereavement Network goes some way to addressing this and is a welcome development.
- 40% of children who die in Ireland die within the first week of life. The HSE has developed national standards for bereavement care following pregnancy loss and perinatal death. These standards will strengthen and guide the development of a palliative care approach for women, babies and families experiencing loss and grief in Ireland's maternity services.

## Priority developments 2016-2020

### The HSE National Development Committee on Children's Palliative Care has identified the following priorities:

- In collaboration with the Department of Health and the National Clinical Programme for Paediatrics and Neonatology, agreement on prioritising new service developments
- A national strategic approach to the provision of in-home and out-of-home respite for children with life-limiting conditions
- The appointment of a National Development Coordinator for Children's Palliative Care incorporating the management and leadership of the Children's Outreach Nurses for Life-Limiting Conditions
- The appointment of a second Consultant Paediatrician with a Special Interest in Palliative Care, to be based at Temple St. Children's University Hospital
- The appointment of additional Children's Outreach Nurses for Life-Limiting Conditions
- A strategic approach to the development of bereavement support services
- Further development of children's palliative care education programmes as well as an innovative research and evaluation programme for the sector
- A strategic approach to workforce planning for children's palliative care
- Further advocacy and communication about the needs of children with life-limiting conditions and their families
- Full integration of existing and new developments with the new National Children's Hospital and with community services.

## Useful links

[www.aiihpc.org](http://www.aiihpc.org)

[www.bereaved.ie](http://www.bereaved.ie)

[www.childhoodbereavement.ie](http://www.childhoodbereavement.ie)

[www.eapcnet.eu](http://www.eapcnet.eu)

[www.health.gov.ie](http://www.health.gov.ie)

[www.hospicefoundation.ie](http://www.hospicefoundation.ie)

[www.hse.ie](http://www.hse.ie)

[www.hse.ie/ccne](http://www.hse.ie/ccne)

[www.hse.ie/eng/about/Who/clinical/natclinprog/paediatricsandneonatology](http://www.hse.ie/eng/about/Who/clinical/natclinprog/paediatricsandneonatology)

[www.iapc.ie](http://www.iapc.ie)

[www.jackandjill.ie](http://www.jackandjill.ie)

[www.lauralynn.ie](http://www.lauralynn.ie)

[www.milfordcarecentre.ie](http://www.milfordcarecentre.ie)

[www.nuigalway.ie/nursingmidwifery](http://www.nuigalway.ie/nursingmidwifery)

[www.olchc.ie](http://www.olchc.ie)

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