



Palliative Care Lead

Strategy and Planning

Room 133, Dr. Steevens' Hospital, Dublin 8, Eircode D08 W2A8

Tel: 01 6352270 Email: sheilagh.reaper-reynolds@hse.ie

Ceannasaí um Chúram Mhaolaitheach

Straitéis agus Pleanáil

Seomra 133, Ospidéal Dr Steevens', Baile Átha Cliath 8, Eircode D08 W2A8

Tel: 01 6352270 Email: sheilagh.reaper-reynolds@hse.ie

Mary Butler TD
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.

28th November 2019

Re.: PQ 46067/19: To ask the Minister for Health the procedures in place for paediatric patients that require palliative care; the age at which children transition into adult care; the way in which such care is determined; and if he will make a statement on the matter.

Dear Deputy Butler,

The Minister has requested the HSE to respond directly to you on these matters and the response is as follows:-

The development of children's palliative care in Ireland is guided by the recommendations contained in *Palliative Care for Children with Life-limiting conditions – A National Policy* (DoH, 2009). The subsequent Model of Care developed by the National Clinical Programme for Paediatrics and Neonatology further sets out the short, medium and long-term vision for the development of paediatric palliative care services in Ireland.

Arising from the 2009 policy the HSE established a team of 11 Clinical Nurse Co-ordinators for Children with Life-limiting conditions (CNC) located as per policy recommendations in paediatric hospitals / units around the country (Table 1). The CNC works to facilitate a smooth transition between hospital and home for the family. The nurses also engage with the child's GP, PHN, pharmacy, school etc. to ensure integrated care for the child in the community. The majority of children who require palliative care in the community have a significant disability and many are supported by early intervention / disability services. The CNC collaborates closely with these services to enhance the care provided.

Table 2 outlines a number of nationally available services and these are described in more detail below.

- The HSE's Primary Care service provides homecare nursing support packages for children with complex care needs. These packages are available to families with children who have life-limiting conditions and who in time may require palliative care.
- National policy also recommended the appointment of a Paediatrician with a Special Interest in Palliative Medicine. The first consultant was appointed to Our Lady's Children's Hospital Crumlin in 2011 and a second consultant was appointed to the Children's University Hospital, Temple Street in 2019. As well as supporting children in these two national hospitals, the role also includes providing advice and support to consultants and health care professionals in paediatric units around the country, and to the Dublin maternity hospitals.
- LauraLynn's Children's Hospice, located in Dublin, provides inpatient respite care for children with life-limiting conditions from every part of Ireland. The service also provides accommodation for parents and siblings. Each year a small number of parents choose LauraLynn for end-of-life care for their child.

- Jack and Jill Children’s Foundation provides a home nursing support service to children under five with neurodevelopmental delay. End-of-life care is also provided to all families regardless of diagnosis.
- The Irish Cancer Society and Irish Hospice Foundation work in partnership to provide the Night Nursing and Nurses for Night Care services. Families can avail of up to 10 nights nursing care.

The provision of end-of-life care for children in the community presents particular challenges because the number of children is relatively small, when compared with adults, and chronic illness can present and progress differently in children. Each child with a life-limiting condition is under the care of a paediatric consultant, whether in one of the national children’s hospitals in Dublin or in their local paediatric unit. The child’s consultant works closely with other healthcare professionals, including the adult specialist palliative care team, and the child’s family in order to determine the best clinical and location of care for the child. This is determined on a case-by-case basis.

Due to improvements in clinical care the outcome for children with life-limiting conditions has significantly improved in recent years, and many children who would have previously died are surviving into adulthood. The transition from children’s to adult services can be daunting for families as the level of support available to adults is often not as comprehensive as it is for children/young people. However, because palliative care is based on the total needs of the person (physical, social, psychological and spiritual) the transition into adult palliative care services may be somewhat easier. International evidence recognises that the transition phase differs for each child and many factors need to be considered such as the child’s illness, prognosis, age and autonomy, the availability of appropriate care and evidence based care outcomes. This means that transition needs to be agreed with the young person as appropriate and their parents. Models of transitional care are still being developed in Ireland – for example the National Cancer Control programme is looking at transition lasting into the early to mid-twenties.

In certain circumstances (based on the assessed need of the young person and their family) young people aged 16-18 years are cared for in the adult specialist palliative care inpatient units (Hospices) closest to them and adult specialist palliative care teams in the community provide care to children at home.

All of the services described above are available free of charge to parents and carers.

The HSE is in the process of establishing an expert group that will advise and make recommendations on optimal service provision for children with palliative care needs. The group will focus particularly on the delivery of care in the community but will consult with key stakeholders from across all care settings. It is anticipated that a report will be available in early 2020.

I trust this answers your question but please do not hesitate to contact me if I can be of further assistance.



Sheilagh Reaper-Reynolds
HSE Strategy and Planning Lead for Palliative Care

Table 1: Support for children with life-limiting conditions provided by the Clinical Nurse Co-ordinator service in CHOs/LHOs/Acute hospitals

CHO	LHO	CNC Service
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		Hospital Location
1	Donegal	Letterkenny General Hospital
	Cavan Monaghan	Our Lady of Lourdes Hospital
2	Galway, Mayo, Roscommon	Galway University Hospital
3	Limerick, Clare, North Tipperary	University Hospital Limerick
4	Cork	Cork University Hospital
	Kerry	University Hospital Kerry
5	Carlow, Kilkenny, Waterford, Wexford, South Tipperary	University Hospital Waterford
6 & 7	Dublin South, Dublin South East, Kildare, Wickow	Our Ladys Children's Hospital Crumlin
8	Louth	Our Lady of Lourdes Drogheda
	Meath	Midland Regional Hospital Mullingar
9	North Dublin	Children's University Hospital Temple St.

Table 2: Services provided by national statutory and voluntary agencies

Service		Delivered by	Delivered in
Homecare packages for children with complex care needs including palliative care	HSE	<ul style="list-style-type: none"> Private agencies through tendering process 	<ul style="list-style-type: none"> Nationally
Consultant Paediatricians – Palliative Medicine	HSE/CHI	<ul style="list-style-type: none"> Our Lady's Children's Hospital Crumlin Temple Street Children's University Hospital 	<ul style="list-style-type: none"> Crumlin & Temple St Hospitals Dublin maternity hospitals Information and advice available to all paediatric units
Inpatient Hospice	Voluntary (Section 38)	<ul style="list-style-type: none"> LauraLynn 	8 beds located in Dublin available nationally
Homecare	Voluntary (Section 39)	<ul style="list-style-type: none"> Jack& Jill Children's Foundation 	Nationally
Night Nursing Service	Voluntary (Section 39)	<ul style="list-style-type: none"> Irish Cancer Society Irish Hospice Foundation 	Nationally
Education for healthcare workers and parents/carers	Voluntary (Section 39)	<ul style="list-style-type: none"> All Island Institute for Hospice and Palliative Care 	Nationally
Education for healthcare professionals	HSE	<ul style="list-style-type: none"> Centre for Children's Nurse Education, Our Lady's Children's Hospital Crumlin 	Nationally