



Palliative Care Lead

Strategy and Planning

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Ceannasaí um Chúram Mhaolaitheach

Straitéis agus Pleanáil

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

23rd December 2019

Re.: PQ 46070/19: To ask the Minister for Health the number of children that required and received palliative care in each of the years 2016 to 2018 and to date in 2019, by CHO and hospital in tabular form; 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 I apologise for the delay in getting this response to you.

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.

The tables below provide data on the number of children with life-limiting conditions who were cared for by three specific palliative care services during the period as requested. It should be noted that the figures in each table cannot be added together as children may access more than one service in a given year. Each child with a palliative care need is assessed and referred to the appropriate service.

Table 1 Number of children in the care of the Clinical Nurse Coordinator for Children with Life-limiting Conditions

CHO	2016	2017	2018	2019 year to date
CHO 1	14	27	37	41
CHO 2	31	39	47	48
CHO 3	36	42	49	44
CHO 4	42	44	62	62
CHO 5	50	33	1*	43
CHO 6	17	21	19	20
CHO 7	45	49	43	42
CHO 8	66	61	32	42
CHO 9	18	33	0	34
National Total	319	349	290	376

*Maternity leave

Table 2 Average number of children in the care of the Specialist Paediatric Palliative Care Team in CHI Our Lady's Children's Hospital Crumlin in a month*

Hospital	2016	2017	2018	2019 year to date
CHO 7 Crumlin	50	65	60	37

*A new specialist paediatric palliative medicine consultant commenced in post in 2019 and data will be collected from Jan 2020.

Table 3 Number of children 0-17 years who received Specialist Palliative Care in an Adult Acute hospital per year

CHO	2016	2017	2018	2019 year to date
CHO 1	4	2	2	2
CHO 2	7	7	3	6
CHO 3	5	1	7	7
CHO 4	12	5	13	10
CHO 5	6	0	1	0
CHO 6	1	0	0	0
CHO 7	0	1	0	6
CHO 8	2	10	6	4
CHO 9	0	0	3	1
Total	37	26	35	36

As well as accessing palliative care services directly, children and families are also provided with a range of support services including the following:

- 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 children 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.

In certain circumstances young people aged 16-18 years are admitted to the adult specialist palliative care inpatient unit (Hospices) closest to them and adult specialist palliative care teams in the community provide care to children at home. This is always based on the needs of the child/young person and their family the capacity of the adult service to provide a clinically safe service.

The HSE's Chief Clinical Officer HSE has recently established 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 the first quarter of 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