

**Ceannasaí Náisiúnta um Chúram Mhaolaitheach**

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**Colm Burke TD**  
**Dail Eireann,**  
**Leinster House,**  
**Kildare Street,**  
**Dublin 2.**

**5th April 2022**

**PQ No.: 14979/22 To ask the Minister for Health the total annual spend on the delivery of age-appropriate oncology palliative care services for children, adolescents and young adults between the ages of zero to 24 in 2020 and 2021, respectively; and if he will make a statement on the matter.**

Dear Deputy Burke,

The Minister has requested the HSE to respond directly to you on this matter and the response is as follows:

Based on UK prevalence data it is estimated that there are upwards of 4,000 children with life-limiting conditions in Ireland. It is expected that at any given time approximately 14-19% of these children are likely to be unstable, deteriorating or dying and therefore in need of palliative care. Notably, deaths in the first year of life account for nearly two thirds of deaths in children. It is further estimated that almost half of these children die in the first weeks of life in the care of a maternity hospital or one of the national children's hospitals in Dublin. Furthermore it is estimated that of those children requiring palliative care 80% have a life threatening disability or neurodegenerative condition while 20% are children and young people with cancer. Therefore, it is estimated that at any one time there are less than 50 children with cancer requiring palliative care support.

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 policy does not distinguish between a cancer and non-cancer diagnosis and the approach to palliative care is essentially the same i.e to enable children with life-threatening illness to live active lives for as long as possible, with a focus on ensuring physical, psycho-social and spiritual comfort; End-of-life care also has the same focus. The needs of each child are assessed by a Paediatric Palliative Medicine Consultant and a Clinical Nurse Co-ordinator, who both work alongside the child's primary physician. The appropriate care pathway is agreed in consultation with the child/young person as appropriate, and their parents.

A child with a life-limiting condition may be referred to palliative care early in their disease trajectory or it could be in the last months or weeks of life – this is determined based on their prognosis and the wishes of their parents. As well as supporting the child and young person palliative care services also support families, and this support continues into their experience of grief and loss.

The National Cancer Control Programme has established a Children, Adolescent/Young Adults (CAYA) Palliative Care Project Board to determine how best to meet the needs of children and young adults up to 25 years of age, including the transition from paediatric to adult services – this work is on-going.

Children with cancer may access a range of services in the community and in hospital – these may be palliative care services specifically or they may be primary care services such as homecare nursing support for children with complex needs. Depending on the child's care pathway they may be in receipt of clinical treatment while at the same time be supported by palliative care. Children and families can also access the services provided for example by LauraLynn, the home support services provided by the Jack & Jill Foundation, The Irish Cancer Society or events organised by Barretstown Camp or the Make-A-Wish Foundation. Although some of these services are not clinical/medical in nature, they all address the psychosocial and/or spiritual needs of the child which are considered fundamental to quality palliative care.

Because comprehensive palliative care includes access to a wide range of services, determined by need rather than diagnosis, it is not possible to quantify the cost of the delivery of palliative care to children with a cancer diagnosis.

I trust this is in order.

Regards,



**Sheilagh Reaper-Reynolds**  
**National Lead for Palliative Care**