

National Lead for Palliative Care

Integrated Operations – Planning
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Ms. Jennifer Whitmore TD Dail Eireann, Leinster House, Kildare Street, Dublin 2

02th October 2022

PQ no. 45454. To ask the Minister for Health the reason that medically complex children are transferred to adult services; the reason that there is no young adult level of care for medically complex children and children needing palliative care; if there are plans to provide services specific to children with medically complex needs; and if he will make a statement on the matter.

PQ no. 45456. To ask the Minister for Health his plans to ensure that a child with highly complex medical needs, when they turn 18, do not have to lose or change vital palliative support, school supports, or respite supports in order that there is continuity of care; and if he will make a statement on the matter.

Dear Deputy Whitmore

The Health Service Executive has been requested to reply directly to the above Parliamentary Questions, which you submitted to the Minister for Health.

Palliative care for children is an active and total approach to care, embracing physical, emotional, social and spiritual elements. With increased survival of children with certain life limiting conditions into adulthood, it is necessary to ensure age appropriate and coordinated care is provided particularly when care is being transferred from paediatric to adult services.

In Ireland palliative care for children (< 18) is delivered through a multidisciplinary and multiagency approach, which includes the Childrens Palliative Care team from Childrens Health Ireland along with regional Pediatricians, G.Ps, Clinical Nurse Coordinators and Adult Palliative Care teams. These teams collaborate on a care plan to ensure the child with complex medical needs receives the palliative care support required to maximize quality of life and relieve suffering. In addition respite and caregiver support is provided by HSE paediatric home care packages along with additional in home support from voluntary agencies such as Laura Lynn Childrens Hospice and the Jack and Jill foundation.

Given that adult palliative care teams are involved in the care plans of children, there are established relationships and communication channels, which support the transition of the child to adult services at the age of 18.

Guidance on best practice for transitioning care is provided to teams in the HSE 2018 *Model of Care for Transition from Paediatric to Adult Healthcare Providers in Rare Diseases.* It has a chapter dedicated to the transition of children with life limiting conditions to adult palliative care services and

emphasizes the importance of involving the young person and family as well as the development of a written transition plan.

I trust this is in order and answers your query.

Regards,

Maurice Dillon

Marie Della.

National Lead for Palliative Care, Integrated Operations-Planning