

Office of the Head of Primary Care South East Community Healthcare HSE Offices, Lacken Dublin Road Kilkenny

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30th March 2023

Mr. Michael Lowry TD Dáil Éireann Leinster House Dublin 2

PQ 15549/23

To ask the Minister for Health the reason terminally ill young children living in the south east are still being denied community paediatric palliative care services, therefore depriving them of the right to die at home; if immediate steps will be implemented to provide this critical treatment to young children in need of paediatric palliative care services; the reason home palliative care is still being denied to children in the South East; and if he will make a statement on the matter.

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PQ 15550/23

To ask the Minister for Health if the recommendations listed in the Bee Wee report 2020 for the clinical governance and operational arrangements for supporting a model of care for children with life limiting conditions towards the end of life is being implemented in the South East for paediatric palliative care services; and if he will make a statement on the matter.

Dear Deputy Lowry,

The Health Service Executive (HSE) has been requested to reply directly to you in the context of the above Parliamentary Questions, which were submitted to the Minister for Health for response.

I have examined the matter and the following response outlines the current position.

South East Community Healthcare area recognises the final report and recommendations outlined in the Clinical Governance and Operational arrangements for children with life limiting conditions towards end of life (Bee Wee report December 2020). The restoration of paediatric Palliative Care Services in the South East has progressed, with particular reference to the following areas:

- The Specialist Palliative Care team for Children is based in Children's Hospital Ireland, Crumlin. This team is a consult, advisory and supportive service which works in close liaison with Medical Teams providing care to children in need of palliative care across the country.
- Progress has been made in relation to the recruitment of a Consultant Paediatrician with a specialism in palliative care for the South East.

- There are two Clinical Nurse Co-Coordinators for Children with Life Limiting Conditions in the South East who support the provision of safe care as required in the home environment.
- Referrals from Children's Hospital Ireland, Crumlin are assessed and accepted by the relevant community and acute services. In accordance with each individual need, an appropriate care package is implemented for each individual case.
- When children are at end of life, they and their families should receive the optimum care as required either in their home or acute hospital setting. Primary Care Services SECH in association with the relevant hospital group aim to ensure the implementation of a comprehensive care package based on individual needs.
- Progress has been made in relation to the development of a robust sustainable long term plan
 for the provision of Paediatric Palliative Care services in the South East. In this regard, there is
 ongoing engagement with Children's Hospital Ireland, Crumlin and all relevant stakeholders in
 both acute and community to progress the required supports in line with the Model of Care
 for Children with Life Limiting conditions.

The South East Community Healthcare Organisation in association with the relevant hospital groups continue to engage and support the families as required.

I trust this information is of assistance to you. Should you have any further queries please do not hesitate to contact me.

Yours sincerely,

Anna Marie Lanigan

Head of Service-Primary Care/Assistant National Director

South East Community Healthcare