



Ein cyf/Our ref: MA-P/VG/2103/19

Darren Millar AM  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

11 June 2019

Dear Darren,

I write following business questions on 3 June when you called for a statement in relation to hospice care for children in Wales.

In particular you raised the recent HIW thematic review 'How are healthcare services meeting the needs of young people?' which was published on 29 March 2019. As part of this review HIW looked at the care and treatment provided to children and young people in the two children's hospices in Wales. HIW found staff were kind and caring and there was good support available to families. HIW also found that young people received care that was tailored to their specific needs and were supported with an extensive range of facilities and programmes to enhance their well-being. Children, young people and their families were involved in decisions about their care, and hospice staff were particularly respectful of their wishes for end of life care and after death.

However, whilst HIW found that young people in general received safe and effective care, it did identify some areas where there was room for improvement, particularly recommendations 17, 18 and 19 of the report relating to environmental risk assessments; arrangements to support communication needs of children, young people and their families, including facilities to support people who use hearing aids; and assessing any unmet demand for palliative care services to ensure children and young people across Wales get the care they need.

My officials have written to Ty Gobaith and Ty Hafan to seek assurances about the actions they are taking to respond to recommendations 17 and 18.

In relation to recommendation 19 and unmet need, it should be noted that the review only looked at the care and treatment provided to children and young people in the two children's hospices in Wales and did not fully consider NHS paediatric palliative care provision.

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

The Welsh Government, in collaboration with the End of Life Care Board, has also put in place:

- Additional paediatric palliative care specialist nurse sessions in each health board
- An All Wales transitional care consultant post
- A paediatric palliative care clinical network
- Bereavement support services for children and young people
- Community Play therapist posts
- Additional consultant support in North Wales
- Funding for paediatric palliative care training
- Mechanisms to access funding to purchase Cold Cots for health boards
- Funding to support Neo Natal posts in South Wales
- Increased access to paediatric hospice at Home in North Wales

Steve Ham, the chair of the End of Life Care Board, has been asked to consider how we respond to recommendation 19 within the HIW report about unmet need and I am advised that the End of Life Care Board will be discussing this report at its Board meeting later this month.

Steve has also advised that paediatric and transitional palliative care provision will be considered as part of a wider service stocktake being undertaken by the End of Life Care Board during 2019/2020.

I trust this information assures you that work is progressing in this area and that actions are in place to take the recommendations from the HIW report forward.

Yours sincerely,

A handwritten signature in black ink that reads "Vaughan Gething". The signature is written in a cursive, flowing style.

**Vaughan Gething AC/AM**

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services