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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal  
Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Tŷ Hafan

Response from: Tŷ Hafan



30 August 2016

Ms Sarah Beasley  
Clerk  
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Dear Sarah

### **Priorities for the Health, Social Care & Sport Committee**

We would like to highlight how together we can make an affordable step change in quality of life for children and families needing paediatric palliative care.

It was a pleasure this week to be able to host Dr Lloyd for a visit and Tŷ Hafan will need no introduction to your committee. Members may however be surprised that as we celebrate 18 years in 2017, we are on a daily basis supporting 260 families at and our work now starts before children are born. It means 22% of the families work with come to us with a child less than 4 months old and 20% of our families receive sibling support and parental support for 5 years or more; adjusting to the loss of a child whilst you have a life to make never truly gets easier. Our community services provide play support, music and complimentary therapies at the hospice and at home. Ty Hafan provides medical, nursing and social support in the Hospice. More and more children, with the benefit of palliative paediatric care throughout life, will live into early adulthood, transitioning into adult services. Having jointly recruited with Cardiff and Vale UHB a full time paediatric palliative care consultant we are ambitious to work with the Deanery to work together to further develop the Paediatric palliative care consultant workforce in Wales.

In 2015, Tŷ Hafan in conjunction with the Wales Institute for Health and Social Care (WIHSC) published a major report '*Palliative care for children and young people in Wales: meeting future needs*'. Mark Drakeford led the official launch. Despite the combined current capacity of Tŷ Hafan and Tŷ Gobaith, and excellent partnerships with our health boards means there is not enough paediatric palliative care capacity to meet the need in Wales. The work initiated recently by Veronica Snow to ensure children with life limiting illness are explicitly included in blue light ambulance priorities in Wales is exciting. This is gap it is an unintended one. When we first set such priorities children receiving paediatric palliative care did not need these services, now they do.

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30 August 2016

Ms Sarah Beasley  
Health, Social Care and Sports Committee  
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We can only do what we do at Tŷ Hafan because of the tremendous commitment and generosity of the Welsh people. They give more than £3 million to fund the care we deliver every year, adding substantial value to the historic government investment in Tŷ Hafan of just over £200,000. In raising these funds we encourage people across Wales to get fit for Tŷ Hafan. We are a major partner when it comes to sports and health. Over 7,000 people have registered with us to undertake major fitness challenges for Tŷ Hafan using wearables to track their progress. In a new partnership with "Give a Penny" our fundraisers will be able to track steps and challenges to walk a kilometer or a 5k rainbow run as a family, ensuring we make a difference to health and fitness and as well as inspiring support for Tŷ Hafan.

Wales is exceptional in the UK in that our government recognizes the need for paediatric palliative care. However, palliative care policy has, never the less for understandable reasons been largely focused on adult services. We believe that needs to change now and we have been working closely with the Welsh Government to explain why. Having the opportunity for Dr Dai Lloyd to see for himself what we are currently providing was a pleasure and it was gratifying that he felt that we have significantly developed the service provision in the time he has known us and the positive impact that makes. During the visit I discussed with Dr Lloyd the need for the voice of children to be heard. I am sure you would agree that this is an issue that transcends party politics and on behalf of Tŷ Hafan, we would be extremely keen for the Committee to consider looking into paediatric palliative care in Wales.

We would also be very happy to engage more broadly with the committee on issues that affect the health of children more widely, including long term conditions and public health.

I look forward to working with you over the Fifth Assembly.

Yours sincerely



**Kate Phipps**  
Chief Executive