

Tŷ Hafan & Tŷ Gobaith Briefing: Supporting Families of a Bereaved Child

Summary

Ahead of the Senedd's debate on petition [P-05-912: Supporting Families with Sudden and Unexpected Death in Children and Young Adults](#), on Wednesday 3 November 2021, Tŷ Hafan and Tŷ Gobaith children's hospices wished to publish this briefing document, highlighting the services we are currently able to offer to families who have experienced the bereavement of a child or young person, what more is needed to support this group, and what we need of the Government in Wales to offer these vital services to more families across Wales.

The aim of this is to highlight the high standards of bereavement support that are available in Wales, following the tragic passing of a child or young person. We hope this can be used to highlight what work can be done – and what more should be done to support those families that unexpectedly lose a child or young person.

Tŷ Hafan and Tŷ Gobaith – How We Support Through Bereavement

As Wales' only children's hospices, together our charities Tŷ Hafan and Tŷ Gobaith offer holistic, child-centered care, free at the point of service, for more than 450 families across Wales, providing over 2500 nights of respite care each year – a service not available from the NHS or Local Health Boards.

Both hospices provide palliative and end-of-life care to children and young people, from perinatal through to bereavement, in the worst instance. As well as our clinical care support, we offer a wide range of services, to ensure that family members are also cared and supported for throughout the duration of their child's life and during bereavements. Our services at end-of-life include:

- End-of-life care and choice of setting – be that at home, in the hospital or at a hospice;
- Bereavement support for family and wider support network;
- Dedicated faith rooms on site;
- Dedicated counselling services;
- Sibling support groups;
- Separate mum and dad support groups;

Tŷ Gobaith, based in North Wales, also provide a specialist cold-room, called the snowflake room. This room, which is a controlled temperature room, allows family members, and wider support networks, to spend time with a child after they have passed away. This allows those family members who may live further away and need to travel, for example, the opportunity to do just that, and say goodbye properly.

When a child who has used Tŷ Hafan or Tŷ Gobaith dies – our support for that family does not stop. We will work with the parents, siblings and wider family members for as long as they need us, offering guidance, support, advocacy and, in some cases, simply a sounding board or a shoulder to cry on. We understand that there is no set timeline on bereavement and

grief, with many families experiencing very different circumstances. Tŷ Hafan and Tŷ Gobaith will always be there for as long as the family need us.

Both hospices are also able to provide support and care for families who lose a child, in most instances to a life-limiting condition, even if they have never used our services previously. We want to be there for everyone that has lost a child or young-person – and the services outlined above are available, free at the point of use, to all who need us.

Tŷ Hafan and Tŷ Gobaith pride ourselves on being the foremost resource in Wales for end-of-life care in children and young people and are proud of the services we are able to offer both the children with life-limiting conditions, many of which sadly pass away before reaching adolescence – as well as their families and wider support networks.

Question to Consider

I have had the pleasure of visiting Tŷ Gobaith children's hospice in my region of North Wales – which provide exceptional bereavement support for the families of a child or young person who has passed away, albeit in very different circumstances to what we are discussing here today.

Families are provided with a choice of end-of-life setting; there are dedicated faith rooms on site; dedicated counselling services; sibling support groups; as well as dedicated mum and dad support groups. When visiting Tŷ Gobaith back in the summer, I also visited what they call the 'Snowflake room' - that is a temperature-controlled room that allows family members to be with their child after they have passed away - and provides opportunities for other members of that child's life to say goodbye in their own way.

The most important aspect of Tŷ Gobaith's work – mirrored by Wales' other children's hospice in South Wales, Tŷ Hafan - is that this work and support network does not stop following the death of a child or young person. These services are there for as long as the family wishes to use them – with many returning to the hospice services years after they have faced the unimaginable and lost their child. While some may wish to use the support groups, counselling services or other support – many wish to simply have a sounding board or shoulder to cry on, and the hospices are able to do just that.

I am urging the Government to recognise best practice, including 2 Wish Upon A Star, Tŷ Gobaith and Tŷ Hafan - learn from the experiences of charities that provide exceptional support for those families who have lost a child, and provide a service that offers care and support before, during and long after the death of a child here in Wales.