tŷ hafan.
where a short life
is a full life

for professionals.

tŷ hafan

the hospice for children in Wales
yr hosbis i blant yng Nghymru

Since 1999, we have helped over 600 families at the hospice and in the community

"At Tŷ Hafan, Ellis is more confident and is able to have fun and enjoy himself. It is such a relief to be able to speak to our Family Support Practitioner about our worries and it's great to know she is always there at the end of a phone if we need anything."

Ceri, Ellis' mum
Pictured: Ellis

where a short life is a full life

For children aged 18 and under and families you are aware of and care for with palliative care needs and life-limiting conditions, Tŷ Hafan can offer bespoke palliative care packages free of charge.

Since 1999, Tŷ Hafan has supported over 650 families at the hospice and in the community. Not only do we provide residential stays at the hospice, we also work in partnership with health and social care professionals to provide specialist palliative care for symptom control and end-of-life care. Where you feel it might be helpful, our community services team can provide support to families to manage the pressure, stress, hurdles and grief they face on a regular basis.

Tŷ Hafan meets the palliative needs of children and families who use our service by recognising the four elements that constitute total care: physical, emotional, social and spiritual. Working with the appropriate professionals, Tŷ Hafan will provide assessment, care planning, implementation and evaluation of a bespoke package of specialist palliative care which meets the needs of every child and family member.

We are able to deliver an excellent standard of care through qualified and trained staff, with extensive experience of palliative care nursing and family support who will work in partnership with you and your Health Board to ensure a safe and effective package is tailored to the needs of the family. Roles available to support this at Tŷ Hafan include:

- Paediatric Nurses
- Family Support and Assessment Practitioners
- Family Support Workers
- Physiotherapist
- Music Therapist
- Specialist Play
- Complementary Therapist

We are monitored by Healthcare Inspectorate Wales under regulations set by legislation, through announced and unannounced inspections. These reports can be viewed online: **www.hiw.org.uk**.

working together

The complex needs of life-limited children and their families can often create a network of multi-disciplinary professionals and organisations involved in their care and support.

Tŷ Hafan can work as part of that team alongside health and social care professionals to ensure a seamless service provision. We will ensure that links are maintained with all professionals involved in the care of each child. This will include information about interventions or changes in a family's situation following a stay at the hospice, or in the community setting.

Our service complements that of other professionals and Tŷ Hafan is uniquely placed to ensure that each family has the range of comprehensive support necessary to meet their needs. The many years of experience caring for children with life-limiting conditions and our professional expertise in palliative and end-of-life care means that our staff are comfortable dealing with the many questions that the children, their families and fellow professionals may have. At Tŷ Hafan, we are happy to provide help and education for families and the professionals who work with them.

Working in partnership with you, we can offer a child with a life-limiting condition specialist palliative care and support both in their homes and in the beautiful setting of our purpose built hospice at Sully. The facilities available to children and families at the hospice, while high spec, maintain a homely and welcoming environment where families, including siblings, can play and relax, thus improving the quality of life for the whole family.

Our approach involves addressing the emotional, social and spiritual aspects of care, as well as managing the physical realities of a child's condition. We provide a service which allows life-limited children, siblings and parents to express their feelings and find new ways of coping. We try to ensure they gain back some control and experience the positive aspects of family life.

Our team responds to the ever changing needs of each family, providing support almost anywhere, whether it is at the hospice, their own home or in hospital. If required and with the parents consent, we may visit a child in a setting such as nursery or school to gain an insight into their individual requirements.

We give families time to rest and time to discuss difficult decisions. We can guide them through the legal, ethical, practical and emotional aspects of death with our specialist end-of-life advice and support. Alongside your teams, we will journey with them through death and bereavement and we are happy to be there as a helping hand for as long as they need us.

For more information or to arrange a visit to the hospice please contact **www.tyhafan.org/what-we-do**

"Partnership working is crucial. It is a core principle running through a number of key policies and priorities and for what is now a shared agenda to achieve real and lasting change, particularly in improving experiences and outcomes for children with life-limiting conditions"

Department of Health (2008)
Better Care: Better Lives
London: Department of Health

making a referral to tŷ hafan

Where there is a diagnosed condition, we accept referrals at all stages of the illness and we may also accept children and young people with complex health needs arising from undiagnosed conditions. The main criterion for acceptance to the service is professional confirmation that:

- The child or young person may die in childhood
- The child or young person is aged 18 or under

You can refer a child at any time. Simply get in touch with our Palliative Care Nurses and they'll work with you to take the next steps forward.

Phone us on 029 2053 2200 and we'll collect the information we need from you. Consent from the person with parental responsibility and, where applicable, the child or young person, is needed.

If you're not sure whether a child or young person is eligible, please call us; we are happy to discuss cases prior to referral and to support initial discussion with families, so that they feel positive about the help we can offer.

In emergency circumstances, we can accept cases to make sure a child or young person gets the necessary support quickly. This is common if an unforeseen end-of-life situation develops.

feedback

If you have had a positive experience working with Tŷ Hafan, please share our service with relevant colleagues in order that as many children as possible across Wales can benefit from the care we provide.

If you have not had such a positive experience, please feed this back to us so that we can improve our service.

Please pass on this brochure or download a copy from our website www.tyhafan.org. We look forward to hearing from you or your colleagues.

Tŷ Hafan is about making the most of a child's life, however long or short that life may be. We help families make lasting memories and support them through every step of their journey.

www.tyhafan.org

Tŷ Hafan - the hospice for children in Wales. Hayes Road, Sully, Vale of Glamorgan CF64 5XX

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