

**tŷ hafan.** two simple words  
which, for our families,  
mean everything.



imagine you've just been  
told your child will die  
before adulthood.

**What would you do? Who would you turn to?  
How would you cope?**

**Unimaginable isn't it? It's every parent's unspoken nightmare that for some becomes a dreadful reality. But for life-limited children, young people and their families in Wales, there is comfort and a helping hand. It's called Tŷ Hafan.**

Tŷ Hafan looks after life-limited children, young people and their families, ensuring they make the most of every precious moment. Not only is Tŷ Hafan able to offer a less clinical, more homely environment for specialist palliative care, but we also offer a much needed source of strength, comfort and support for the whole family. From diagnosis to bereavement and beyond we take our support right into the heart of the family home. We do this completely free of charge for families in Wales that need us.

But quality care comes at a cost. Not being part of the NHS we receive no guaranteed statutory funding. To continue to offer care and support to our families we need your help.

Help us alleviate the terrible strain that coping with a life-limited child or young person imposes on family life. With your generosity we offer short breaks to give families desperately-needed time out, which can include accommodation for any family member that wants to stay over. We also provide relief and support outside the hospice, at home and in the community to ensure that each child has a comprehensive care programme.

Tŷ Hafan is about a positive approach to life and death that creates and cherishes a lifetime of memories. It's about improving the quality of life of these children and their families. It's about joy, laughter and friendship. It's about allowing families to feel normal and do normal family things. The simple stuff of life you'd want for your own family, your own child.

So please, help us be a rock for these families. Help us fill their lives with comfort, care and support. Help them make the most of the time they have left together.

[www.tyhafan.org](http://www.tyhafan.org)

Tŷ Hafan - the family hospice for young lives. St. Hilary Court, Copthorne Way, Culverhouse Cross, Cardiff CF5 6ES  
Tel: 029 2067 2060 Fax: 029 2067 2061 Registered Charity No: 1047912. Tŷ Hafan® is a registered trade mark.

# summer and mabon's story

On first meeting six year old Summer and four year old Mabon you might think they are just like any other young children who seem to have an endless supply of energy and for whom the world holds no fear.

These are, however, symptoms of a condition called San Filippo (a mucopolysaccharide disorder known as MPS). In Summer and Mabon's case, the enzyme which breaks down their mucopolysaccharides is missing which results in them remaining in the cells causing progressive damage.

Both children are at the first stage of the condition where their hyperactivity can mistakenly portray them as

'naughty children who are not being effectively disciplined'.

Managing her children's needs without adequate support on a day-to-day basis is a monumental task for mum Diane.

**"At Tŷ Hafan, my children have that one-to-one care which is often very difficult for me, as their sole carer, to provide at home."**

"Staying together at Tŷ Hafan enables me to just add to their care and spend time with my children, enjoying their happiness. This is a luxury we otherwise would not have.

"The children love having a large space where they can race about freely which they so need. The amount of natural light gives a positive air to the place and also gives a sense of freedom, often so lacking when you're a lone carer.

"It means I can also use our time there to catch up with paperwork connected to their condition or on rare occasions, just drop my things in my room and sleep, knowing the children are safe and happy.

"When we were first referred to Tŷ Hafan I was not aware of the breadth of services it provided. In addition to the one-to-one care we receive at the hospice, our

Tŷ Hafan Family Support worker also helps me deal with other organisations and battles which, as the children's mum, I have the responsibility to take on for them whilst at the same time attending to them."

Sadly, Summer and Mabon's condition means that by the time they reach their teens they will become immobile and will gradually lose the ability to communicate.

It also means that Diane will lose both her precious children before they reach adulthood.

**How would you cope?**



# 1 You can count on my support.

(Please use BLOCK CAPITALS) Title ..... Forename .....

Surname ..... Date of birth .....

Company name (if applicable) .....

Full Address .....

Post Code .....

Tel ..... Mobile .....

**Help Tŷ Hafan save money on postage – join our email list!**

**Email** .....

# 2 Here's my regular gift of:

£10 monthly  £15 monthly  Other Please state amount £ ..... monthly

Please fill out your Direct Debit mandate below and don't forget to tick the gift aid box! .....



## Instruction to your Bank or Building Society to pay by Direct Debit



Please fill in the form and send to Tŷ Hafan, Head Office, St Hilary Court, Copthorne Way, Culverhouse Cross, Cardiff CF5 6ES

**Name and full postal address of your Bank or Building Society**

To the Manager	Bank/Building Society
Address	
Post Code	

**Name(s) of Account Holder(s)**

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**Bank/Building Society account number**

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**Branch Sort Code**

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**Bacs Service User Number**

2	4	9	5	0	0
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**Reference Number**

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**Instruction to your Bank or Building Society**

Please pay Tŷ Hafan Direct Debits from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee.

I understand that this instruction may remain with Tŷ Hafan and if so, details will be passed electronically to my Bank/Building Society.

Signature(s)
Date

Banks and Building Societies may not accept Direct Debit Instructions for some type of accounts

# 3 I can't commit to a regular gift, but would like to make a donation:

- Please accept a cheque / CAF voucher for £ ..... payable to Tŷ Hafan
- Please accept my credit / debit card donation - Debit my Mastercard / Visa / Debit

Cardholder's Name ..... for the sum of £.....

Address (if different) .....

Post Code .....

Contact tel ..... Card No .....

Debit Card Issue No ..... Issue Date ...../..... Expiry Date ...../..... Security No: .....  
(if applicable) (last three digits on reverse of card)

Signature ..... Date .....

# 4 Increase your donation with the Gift Aid Scheme

*giftaid it*

- I am a UK taxpayer and I would like Tŷ Hafan to reclaim the tax on my donation through the Gift Aid Scheme (an extra 28p for every £1 donated). This declaration also relates to all donations I have made to Tŷ Hafan in the past four years and all donations I make hereafter until I notify you otherwise. For donations to qualify for Gift Aid you must pay income tax or capital gains tax equal to the amount claimed in the tax year.

## Please send me further information on:

- Tŷ Hafan events
- Crackerjackpot
- Leaving a gift in my will
- How my company can support Tŷ Hafan
- Becoming a volunteer
- Starting or joining a "Friends of Tŷ Hafan" group
- Fundraising
- Other – please specify .....

## Please return this form to: Tŷ Hafan, Head Office, St Hilary Court, Copthorne Way, Culverhouse Cross, Cardiff, CF5 6ES

Tŷ Hafan values your support and promises to respect your privacy. The data we gather and hold is managed in accordance with the Data Protection Act (1998). We will not disclose or share personal information supplied by you with any third party organisation without your consent. By providing your details, you will be indicating your consent for Tŷ Hafan to contact you by email, letter or by phone to inform you about future fundraising activities and appeals, unless you have indicated an objection to receiving such messages by ticking a box below.

I do not wish to be contacted by: email  telephone  post

For office use only ..... 024148 (feb11)