

Autumn/Winter 2024

cwtch

from Tŷ Hafan Children's Hospice

This issue:

Daniel's story

Remembering Jammy

A day in the life of...
a Lead Nurse



Tŷ Hafan

CHILDREN'S HOSPICE
HOSBIS I BLANT

Play our Christmas raffle

The Tŷ Hafan Christmas raffle opens on **3rd October**.
Play to win some huge prizes!

Every **£1** will get you a chance to win fabulous prizes and a guarantee you'll be helping to reach every child and family in Wales that need us.

Win big this Christmas!

First prize
£3,000
or a holiday
to **Sardinia***

Second prize
£500

Third prize
£50
M&S Voucher
(10 vouchers to be won)

Win more with fast-track entries

Get your tickets **before 20th October** to be entered into our fast-track draw, giving you more chances to win!
With a fast-track entry, **you could win £500 or a hamper full of treats.**

How to enter

Find out how to enter the raffle and read the terms and conditions by scanning the QR code or by visiting:
www.tyhafan.org/support-us/raffle

The closing date for the raffle is **11th December** and the draw will take place on **19th December**. The results will be available on our raffle webpage on the date of the draw. **Good luck!**

*to the value of £3,000.

Hannah, from Caerphilly, won the top raffle prize in 2022!



"I wanted to enter the raffle to help raise funds to support Tŷ Hafan and the amazing work that they do.

"I feel great satisfaction that I supported Tŷ Hafan and, when I found out I won, I couldn't believe it. I never expected to win, let alone win first prize!

"I'm so grateful to everyone at Tŷ Hafan - I plan to use the prize money to take my three-year-old twins on a holiday this year."

Congratulations, Hannah!





Contents

Welcome	03
#ReachEveryChild	04
A day in the life of... a Lead Nurse	06
Let's get together!	08
Sophie's memory jars	10
Home education Tŷ Hafan style	11
Spotlight on... Family Support Volunteers	12
Remembering Jammy	13
Daniel's story	14
Maria and Fynley's story	16
Chocolate orange cookies	17
Fundraising heroes	18
Family Support events	20
News from our care services	22
'All about me' by Math	24
Tŷ Hafan in Numbers	25
Your donations count	26
Donation form	27

Get in touch

We would love to connect with you!

If you would like to find out more about what we do or want to fundraise for us, get in touch with us through our website, by email, over the phone or on social media.



www.tyhafan.org



supportercare@tyhafan.org



02920 532 255



Welcome

Welcome to the latest edition of *Cwtch* magazine. I hope you enjoyed the summer.

I joined Tŷ Hafan at the beginning of June and found the charity to be such a welcoming place. So much is going on to ensure we continue to provide the best possible care and support to children and their families.

It has been inspiring to see the commitment and professionalism of colleagues, including volunteers, working across the organisation.

Our work is, of course, dependent on the ongoing support of so many individuals and organisations, to whom we are indebted. You will find more details of how you can get involved in supporting the work of Tŷ Hafan in this edition of *Cwtch*.

Children's Hospice Week, which took place between 17th and 23rd June, provided an opportunity to both highlight the critical work of Tŷ Hafan and to make the case for an increase to our ongoing funding from Welsh Government, which currently covers only 14% of our costs for providing care.

We were supported in this task by our huge #ReachEveryChild butterfly (read more on page 4): an amazing piece of art created by our staff, volunteers and some of the children supported by Tŷ Hafan and Tŷ Gobaith hospices.

In the meantime, and on behalf of everyone at Tŷ Hafan, we wish you all the best and thank you for your ongoing support.

Diolch!

Irfon Rees
Chief Executive Officer



Gello

#ReachEveryChild



During Children's Hospice Week in June, we displayed a giant butterfly on the steps of the Senedd as we, along with Tŷ Gobaith, renewed our call for sustainable funding from the Welsh government.

We only reach **1 in 10 children** in Wales with a life-shortening condition, which means that thousands of families across the nation live their child's short life alone and isolated.

We must reach every child who needs us but to do that, we need more funding.

So, we're asking the Welsh government for planned, recurrent funding to cover 21% of our care costs annually, so that we can reach more children. That compares to last year's funding of 14%.



#ReachEveryChild

Donate



To raise awareness of the challenge ahead of us as we strive to reach every child, we created a 6-metre by 8-metre fabric butterfly made up of 3,655 smaller butterflies to represent the number of children in Wales living with a life-shortening condition.

10% of those smaller butterflies were in full colour to represent the children we already reach, and the rest were grey to represent the children we're still yet to reach.

Why a butterfly?

Butterflies are a symbol of the children's hospice movement in the UK, representing the short but beautiful lives of children with life-shortening conditions.



Our Graphic Designer, Ann Wright, along with Penny Collins, our Handcrafted Project Engagement Officer, and an army of volunteers, led the creation of the butterfly, which took two weeks to complete.

You can help

There's still a chance to be an important part of our #ReachEveryChild campaign – join our call for sustainable funding.

If you live in Wales, you have a local Member of the Senedd (MS). You can write to your MS in just a few clicks through the website www.writetothem.com and, if you're not sure what to say, we have a letter that you can copy and paste on our webpage www.tyhafan.org/reacheverychild.

Thank you!



On Tuesday 18th June, during Children's Hospice Week, we displayed the #ReachEveryChild butterfly on the steps of the Senedd and spent the morning speaking to Members of the Senedd and the public.



14 Members of the Senedd, including the Health Minister, took time to meet with our team and bereaved parents Jonathan and Catherine Bugg, who bravely shared their son Daniel's story with them.

Did you know...?

Lots of the coloured butterflies were decorated by children supported by Tŷ Hafan and Tŷ Gobaith children's hospices.



A day in the life of... a Lead Nurse



Adrian is a Lead Nurse at Tŷ Hafan, and he has given us a behind the scenes look at what his day-to-day role is like!



“I usually do early shifts with a 7 am start or late shifts which start at 1.30 pm. My day starts by making sure that the right staff are allocated to the children based on their skills and what the child needs,” says Adrian.

“Straight away, I’m on hand to manage any issues and take care of the daily checks on equipment and medication,” he adds.

In a children’s hospice, the cliché is true: no two days are the same. The team can – and do – plan each day, but there’s always a very real chance that emergency stays or end-of-life care admissions will come in.

“We’re always prepared for urgent or end-of-life admissions and, focusing on the needs of that child, making sure we have the right medication and equipment. Meeting the family’s needs is our priority,”

Adrian explains.



Donate



“A Lead Nurse leads the shift. We’re the people colleagues come to for troubleshooting, advice and support. We lead one-to-one meetings with the team, reflect on the care that we’ve given and take care of the team’s wellbeing.



“We also do a lot of governance work like audits, checks, looking at – and implementing - feedback from families, making rotas and... the list goes on!”

Because medical care advances rapidly and the needs of the children we look after are becoming more and more complex, it’s crucial that Tŷ Hafan stays ahead of the latest treatments and technologies to provide a seamless service between home, hospital and hospice.

“Innovation is a big part of my role,” Adrian explains. “When new equipment, technologies and techniques come in, we do audits and testing to see if they would be suitable for Tŷ Hafan and the children we look after. Thinking outside the box about how we can reach as many children as we can and meeting their often very complex needs is so important for us.

“We’re privileged to work with the children and families here. I came to Tŷ Hafan from A&E which is really fast paced. I didn’t have time to talk to people. Here, I have that opportunity to learn more about them, their personalities and their conditions.”

“Here, it’s often about long-term care and helping children live a fulfilling life. It’s about getting to know them, looking at them as a whole and then asking how we can help enhance their lives.

“I really love my job. I know that might seem strange because not everyone loves their job, but I do love coming in and working with families and the team.



“A lot of people say they couldn’t be a nurse at a children’s hospice. So, I always say that it’s lucky that there are people who can!”

Thank you, Adrian!



Join Tŷ Hafan!

A career at Tŷ Hafan is inspiring and fulfilling. When you work with us, you’ll play a big part in our mission to give vital support to amazing children and families in Wales who need us.

Plus, you’ll be able to enjoy:

- 30 days holiday (+ more with service) and Bank Holidays
- Excellent benefits
- Professional development opportunities
- A friendly, supportive work environment

If you’d like to work at Tŷ Hafan, we would love to hear from you!

To find out more about working at Tŷ Hafan and discover our latest vacancies, email us at careers@tyhafan.org or go to: www.tyhafan.org/careers

Let's get together!

The Tŷ Hafan 2024/25 events calendar is full of opportunities for us to get together, have some fun, try something new and raise money for children in Wales whose lives will be short.



The Dark Runs

The Dark Runs have returned for 2024, this time at Cyfarthfa Castle, Caldicot Castle and National Botanic Gardens of Wales.

These family fun runs start as the sun goes down, so the dress code is spooky, bright, glow in the dark or neon dress up. Not a runner? No problem! You can run, jog or walk and the routes are wheelchair accessible*. Dogs are welcome to the Cyfarthfa and Caldicot Castle Dark Runs if they're kept on a lead.



Event details

Cyfarthfa Castle: 25th October
 Caldicot Castle: 26th October
 National Botanic Gardens of Wales: 2nd November

*The Cyfarthfa Castle route features inclines and declines.

[Sign up here](#)

www.tyhafan.org/darkrun



Tŷ Hafan Christmas Concert

Treorchy Male Choir and Treorchy Comprehensive School Choir are coming together to kick off the festive season in style, along with special guest Callum Scott Howells. Join these three adored Welsh acts for matinee and evening performances as they sing Christmas classics all in support of Tŷ Hafan.

Kindy supported by

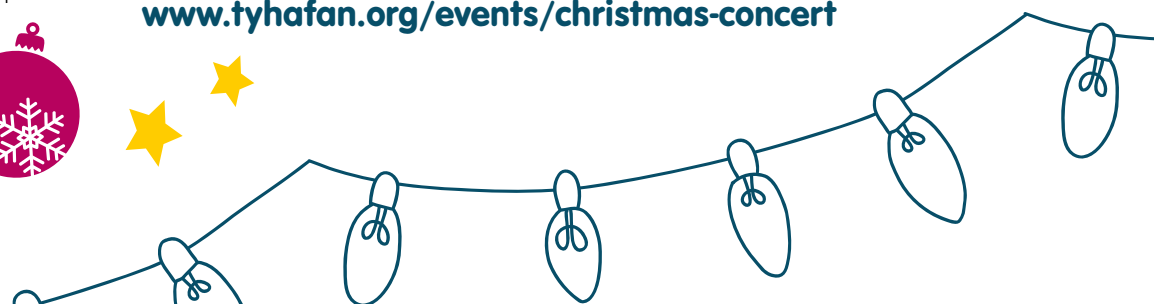


Event details

Sunday 1st December
 Hoddinott Hall
 Wales Millennium Centre, Cardiff
 Matinee: 2.30 pm
 Evening performance: 7.30 pm

[Book tickets](#)

www.tyhafan.org/events/christmas-concert



Donate



The BIG Quiz

Get your heads together at DEPOT in Cardiff in February for a quiz to raise money for Tŷ Hafan. With a live band on the night, and a bar and street food to keep your brain fuelled, this is a new event in the Tŷ Hafan calendar and is set to be a lot of fun!

Event details

Doors open 6 pm, quiz at 8 pm
20th February 2025
Food & drink | Live music | Raffle

Sign up here

www.tyhafan.org/events/thebigquiz



Firewalk 2025

After the popularity of our firewalk events over the past few years, we just had to bring this event back for 2025! We would love it if you braved the coals with us in March at Cardiff City Football Stadium. No experience is required – you'll get all the training you need on the day.

Event details

Cardiff City Football Stadium
9th March 2025

Sign up here

www.tyhafan.org/events/firewalk

Kindy supported by



2025 CHALLENGE EVENTS



Welsh 3 Peaks

The Welsh 3 Peaks event is returning for its 27th year and, as always, we know this is going to be a tough but extraordinary challenge. This flagship event sees teams scale Yr Wyddfa/Snowdon, Cadair Idris and Pen-y-Fan in one day!

The Welsh 3 Peaks challenge is taking place in June 2025.



Register your interest

www.tyhafan.org/events/welsh3peaks

TCS London Marathon & ABP Newport 10K and marathon

All our charity spaces have been filled for the TCS London Marathon 2025, but you can still run in support of Tŷ Hafan if you have a general entry space.

Please email

events@tyhafan.org to let us know if you'd like to run for us.



Next year's ABP Newport 10K and **marathon** is on Sunday 13th April and it would be marvellous if you could run for Tŷ Hafan!

Book your space

Call or email events@tyhafan.org

Sophie's memory jars

We hold regular memory making events with families who have a child who has died. 



You'll need:

- A bag of table salt
- Coloured chinks
- A jar with a lid
- Sheets of paper.



Sophie says...

👂 Creating memory jars gives families a great opportunity to share and explore their memories together and gives a lasting, unique reminder of the person they want to remember. This activity can also give family members a chance to learn about each other's favourite memories, which can be very special. 🗣️

How to make a memory jar

- 1 Think about your loved one... What are your favourite memories of them? What are the important dates in the year that help you remember them - perhaps their birthday? Choose five or six memories to be layers in your jar.
- 2 Fill your jar with salt and lay out your sheets of paper - one for each memory or special date. Pour salt onto each sheet until your jar is empty.
- 3 Rub chalk onto the grains of salt until they're the colour you'd like, using a different colour for each section.
- 4 Gently pour your coloured salt into your jar in layers - you can move the jar around to create different effects and layer the colours however you like.
- 5 Once all your salt is in the jar, tap the jar so that the salt settles and fill the remaining space with plain salt or cotton wool to stop your coloured layers moving.
- 6 Secure the lid.  

Tip

Make a key to show what each colour represents (you can do this with a sticky label, paper or permanent marker).



Home education Tŷ Hafan style!

We are delighted to introduce a new role to Tŷ Hafan – and the first of its kind for children’s hospices UK-wide.

Katie Simmons has taken on the role of Children’s Rights and Education Practitioner, making sure that the children who access Tŷ Hafan can also access an appropriate education.



Katie can offer a time-limited programme of regular lessons, either in the child’s home or at the hospice, to help children feel more able or confident to access their statutory education. Katie keeps these lessons fun, interactive and led by the child’s interests and abilities.

Some children can’t go to school in the winter because of the increase in illnesses or are simply too unwell to attend school at all. Sometimes schools aren’t equipped to meet a child’s deteriorating condition or complex medical needs and this new role gives children more opportunities to access some education and hopefully prevent them falling too far behind their peers.

If a child is non-verbal but still cognitively able, we use equipment and techniques to help them engage. With the Eyegaze technology, a child with limited speech and mobility can engage with the lesson just by moving their eyes, for example doing sums on the screen.

Occasionally siblings can find themselves unable to engage in formal education, sometimes because of caring responsibilities or the impact of bereavement. Katie will advocate for them, encouraging a return to

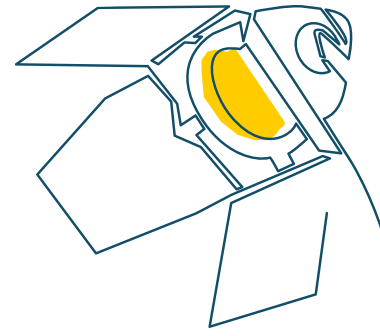
school and, in the short term, may be able to provide some educational support so they don’t miss out on an education.

“Under Article 28 of the Children’s Rights Act, all children are entitled to an education, says Katie.

Children deserve an opportunity to learn and be taught key skills and subjects that will benefit them, no matter what difficulties they might have in their lives.

Kelcea from the Youth Board helped interview me alongside two senior colleagues. She came up with her own questions and gave feedback on my answers. She grilled me!

She found that being part of the interview process helped her feel empowered and was a valuable insight into how to conduct yourself during job interviews. We are now looking at having a young person on the interview panel for roles across the charity!



Spotlight on...

Family Support Volunteers

Because we currently only support around 1 in 10 children with a life-shortening condition, we urgently need to reach more families in their homes and communities.



Family Support Volunteering brings volunteers into family homes and local areas, helping them with tasks like gardening, cleaning, DIY, driving, life admin and, depending on the family's needs, befriending or accompanying families on day trips to be an extra pair of hands.

This started as a pilot project in Swansea and Neath Port Talbot, and we've now opened it across South Wales.

To make sure the right people with the right skills are matched with the right families, we've created a bespoke training program and induction process.

Since the pilot project launched last year, 12 Family Support Volunteers have been inducted, and we're pleased to say that interest in being part of this service is growing all the time.

Debbie, our Family Support Volunteer Manager, says:

“The gift of time is priceless. By donating your time and skills to the families who use Tŷ Hafan's services, you provide much-needed support to families while they face the incredibly difficult challenges of having a child with a life-shortening condition.”

This is a rewarding and flexible way to volunteer and make a real difference to families going through the most unimaginable difficulties.”



Get in touch

If you're a Tŷ Hafan family member who wants to find out more about this project, email debbie.allison@tyhafan.org.

To become a Family Support Volunteer, go to www.tyhafan.org/support-us/volunteer-for-ty-hafan or scan the QR code.





REMEMBERING JAMMY



Get involved

Digital art is a fantastic way for the children and young people we work with to have fun and express themselves! If you have digital art experience and would like to lead a session at the hospice, please email sophie.knapp@tyhafan.org



It's our privilege to get to know the incredible families and children who access Tŷ Hafan.

Today we want to tell you about Sam Greenslade (aka. Jammy!), an amazing young man who has sadly died, but whose legacy lives on through his art.

Jammy, from Ely in Cardiff, had Duchenne Muscular Dystrophy and was known for his great sense of humour and true artistic talent.

He was so talented, in fact, that he was studying photography and digital art at the University of South Wales at just 15 years old!

Jammy died in January 2022, but we have some incredible reminders of him displayed in our hospice. Inspired by his love of physics, cosmology and quantum mechanics, Jammy's digital artwork took second place in the Cardiff Photo Marathon competition, and we are so proud that we now display the winning photos on the wall in our hospice.



Daniel's story

Daniel was my youngest child, and little brother to Hannah, Charlotte and Ethan. Except he wasn't little! At 14, Daniel was over 6ft tall and blossoming into a fine young man.



He was cheeky, funny and a total joker. He loved Lego, he loved sharks and he particularly loved food. Chicken fried rice was the answer to any number of difficulties!

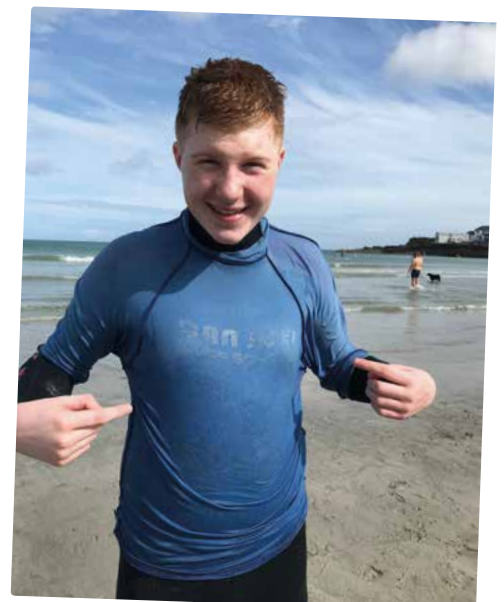
“Daniel was also autistic and this governed his personality quite a lot. He was very direct – he didn't like going around the houses! We knew what made him happy and what made him sad.”

When he told us his right leg was hurting and I found a lump, we were told it was probably just an infection. But an MRI scan showed a tumour was eating the bone.

Daniel started chemotherapy two weeks later, and soon the decision was taken to amputate his leg just above the knee.

A year later, he was doing so well. He was vibrant – cheeky, back at school, doing boxing and walking a kilometre on his prosthetic leg, which he called 'Steve'. Daniel was the tallest of us all and 'Steve' was massive!

Then he told us his good leg was hurting.



Donate



“We tried not to be terrified, but we were.”

A scan found another massive tumour in his leg and, when we found out the cancer was in his lungs, we were knocked for six.



Before going to Tŷ Hafan, Daniel said he'd wanted to die at home. He wasn't sure about Tŷ Hafan at all. I think he hated it because he knew what it ultimately meant for him.

I was aware of it as a local charity, but as a mum of healthy children, you just don't want to have to think about it, do you?



Daniel started going to the hospice when he was in a wheelchair because he could go there to shower himself. Having space and privacy meant a huge amount to him. He started to tell us, "I quite like it there."

He got to know the Tŷ Hafan nurses, Sophie and Adrian, and the trust between them grew. That trust was so important, especially in those last few weeks of his life when Daniel couldn't speak.

Two weeks before Christmas, Daniel told us he was ready to go to Tŷ Hafan. We knew he was deteriorating but hadn't realised he was at that stage.

I can remember wheeling him out of the house and realising I was probably never going to bring him home again.

“I would not wish our experience on anyone. But for anyone going through our experience, I only hope they have a Tŷ Hafan to help them.”

Daniel and his family had Tŷ Hafan to help them thanks to your support. No family should have to live their child's short life alone. Thank you for being there for families like Daniel's.



Maria and Fynley's story

To Fynley, Maria was 'Nana'. He was her 'special little onion'.



"He'd cwtch into me and his mum, Shannon, on the sofa and I'd sing Elvis and Disney songs to him before bed. Those moments are so precious."



When Fynley was born, he struggled to breathe. Within weeks he needed oxygen tubes and a tracheostomy. As he became more poorly during his first Christmas, the family were told about Tŷ Hafan.



At first, we thought it was just somewhere children went to die, but we couldn't have been more wrong. Tŷ Hafan gave us space and time to just be together, making memories. Swimming in the hydrotherapy pool was wonderful. He loved being in the water.



Alongside care for Fynley, Shannon, Maria and her two girls, Sasha and Mia, received comprehensive family support at both home and hospice - support that continues through their bereavement and beyond.



I wouldn't have thought about making keepsakes, but his memory box is one of the most precious things I have. Fynley died four years ago but they still support us so much. They know him and they remember him. When I'm at Tŷ Hafan, I'm still Fynley's Nana. That means the world to me.



By including Tŷ Hafan in your Will, you make sure that Nanas like Maria always have the support they need to keep precious memories alive.

For more information

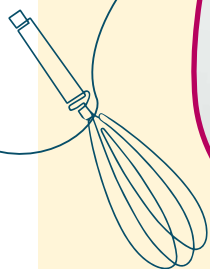
For more information on our free Will writing offer, go to tyhafan.org/will-you, call our Supporter Care Team on 02920 532255 or email supportercare@tyhafan.org



Tŷ Hafan Chefs



Rob, one of our talented Tŷ Hafan chefs, specialises in desserts and one of his favourite winter bakes is these yummy chocolate orange cookies!



Chocolate orange cookies

Ingredients

1 egg
1tsp vanilla extract
100g butter or vegan alternative (unsalted)
75g caster sugar
75g demerara sugar
25g cocoa powder
150g self-raising flour
1/2 tsp bicarbonate of soda
1/2 tsp baking powder
1/2 tsp salt
Zest of an orange
157g (equivalent of a Chocolate Orange) of orange-flavoured chocolate

Method

- 1 Preheat your oven to 180°C (160°C fan) or Gas Mark 4
- 2 Line the baking tray with baking paper or lightly grease it with unsalted butter
- 3 Combine your butter and both of your sugars
- 4 Mix in the vanilla extract and egg
- 5 Add the flour, cocoa, bicarbonate of soda, baking powder and salt until a soft dough has formed
- 6 Chop the chocolate orange up roughly, zest the orange and add both to the dough and mix again
- 7 Form into balls and space them evenly across your baking tray
- 8 Bake for 12 minutes and leave to cool.



Superstar sisters

9-year-old Kooko and her 7-year-old sister, Anorkor, are long-time Tŷ Hafan fundraisers and we love hearing all about what they get up to!

This summer, these superstar sisters took their fundraising to new heights...

Last year, Kooko walked 15 miles to raise money for Tŷ Hafan, the year before she walked 10 miles and the year before that she walked five miles! So, this July, to keep her theme going, she walked a very impressive **20 miles** for Tŷ Hafan! Kooko, along with her mum, Ceri, walked 43,000 steps in 11 hours and has raised a huge **£912** for us.

Anorkor has also been busy this summer. She organised a bake sale in her local area, where she raised **£75** and she had lots of fun looking after her stall. She baked cupcakes with Tŷ Hafan cake toppers, chocolate crispy cakes and, with a bit of help from Grandma, fruit and lemon cakes!



Here's a BIG 'thank you!' to these brilliant fundraisers - we're so impressed with your hard work and delighted that you've chosen to support Tŷ Hafan! 

Fundraising for Tŷ Hafan

Inspired by this story? Fantastic!

The world is your oyster when you fundraise for Tŷ Hafan. You can host an event, take on a challenge, make and sell or do something completely unique!

Our Supporter Care Team will be with you every step of the way. Get in touch with them by emailing supportercare@tyhafan.org or calling 02920 532 255.

Donate



BE A FUNDRAISING HERO

Meet Claire, our Community Fundraising Manager



I'm Claire and I'm the Community Fundraising Manager at Tŷ Hafan. My team, which is made up of me and the fabulous Helen and Shelley, is here for anyone who fundraises for Tŷ Hafan in their local community.

It's our job to make sure you get as much support as you need when you fundraise for us, whether that's ideas and inspiration, getting fundraising materials, tips for organising your event or help with paying in the money you raise.

Here are some of our favourite tips to help you maximise your fundraising.



Claire says...

Tell people what you're doing and ask people to share your fundraiser with their connections – don't be afraid to shout about it! You never know what your story will mean to somebody, even if you don't know them.



Shelley says...

Make sure you allow yourself time to prepare and promote your fundraiser and use social media when you can.

When you're fundraising, always remember how grateful we are that you have chosen to support Tŷ Hafan. The Community Fundraising Team is here to support you every step of the way.



Helen says...

Get creative with your fundraising! Try something new that you think will spark people's curiosity but try not to overcomplicate things - keep it as straightforward as possible.

Make sure you let us know about your fundraising so that we can support you and give you a range of Tŷ Hafan fundraising resources.



Get in touch

We're always here to support you. Get in touch with our Fundraising Team by calling us on **029 2053 2255** or emailing supportercare@tyhafan.org.



FAMILY SUPPORT EVENTS

Our Family Support Team is often on the road, bringing family events into Welsh communities. These events help families going through similar challenges build relationships, access support and have fun closer to home.



Events for mums

Regular coffee mornings give mums a chance to meet up with other people who understand their experiences, as well as Emily and Amy from the Family Support Team.



Crafting and pamper evenings at the hospice are popular with mums too, giving them an opportunity to chat, offload and connect with each other.

We need to offer the events that the families want – not just what we think they want! - so, following a poll, some of the mums have chosen axe throwing, mini golf and afternoon tea recently.



Events for dads

Dads often need different kinds of support from other family members. Family Support Worker, Dan, works closely with dads and has built an incredible community of group and one-to-one support.

The dads' group has its own football team, and they play matches against Principality Building Society (thanks for

providing the dads' team kits, Principality!), 2 Wish Cymru, Advocates and Angels and South Wales Police, just to name a few teams!

Dan leads an online community of dads too, with a monthly Zoom meet-up called Talking Nonsense and an online gaming group.



Donate



Events for families

We love to get out and about with families and day trips are a terrific way to have fun and connect.

We are so grateful that our corporate partners are sometimes able to give us free tickets for families to enjoy events, including Wales football and rugby matches.

Just recently, some of the children and families went to Colliers Farm in Treharris, Folly Farm and Dinosaur Park in Begelly and Taylor Swift's Eras Tour in Cardiff! ★



These opportunities are fantastic for families to go to fun and accessible events without having to pay big prices.

Our Community Hubs are also hugely popular with families, with inclusive games and crafts for the children, a chance for the adults to unwind with massage and time with our Family Support Team.

Events at Christmas



Christmas is an emotional time at Tŷ Hafan, and it can be exceptionally tough for families whose child has died. Having group and one-to-one time with families is crucial at this time of year.

Christmas crafting, like wreath making, is popular with the mums' group every year. Plus, we hold a Christmas market at the hospice with the support of local vendors!

The annual Christmastime dads' meal out is an opportunity for dads to get together to talk candidly to each other about their feelings and experiences.

The dads who have a child who has died get together to make Christmas decorations in memory of their children, and we do a Christmas quiz.

And, of course, our Christmas Candlelight service is a special date in the diary in December.



Your support means families facing the most difficult times can be supported much closer to their homes. Thank you.



News from our care services



ADAPTING OUR SERVICES

Right now, we only reach 1 in 10 children in Wales with a life-shortening condition. Our ambition is that when a child's life will be short, no family should have to live it on their own.



To make this ambition a reality and reach every family in Wales who needs us, we must re-align our services. Our goal is that every family whose child's life will be short will have access to the right care, at the right time, in the right place and delivered by the right person.

This year, we've been working hard to further develop our care and community services so that we can reach more families.

We've introduced our Family Support Volunteer project (read more on page 12) to give families practical support in their homes, and we've introduced the role of Children's Rights and Education Practitioner (read more on page 11) so that children can be supported to engage in education that meets their complex medical needs and to advocate the importance of their rights enshrined in the UNCRC.

We're trying to make our specialist resources more available to families by encouraging them to use the hospice-based rooms and activities like the hydrotherapy pool, sensory room and inclusive playground on a drop-in basis, and by taking our specialist teams and equipment to community venues so families can access support closer to home.

We have been developing our cultural competency skills by meeting with black and ethnic minority families to find out how we can better meet their needs. We are also working with Swansea University on a Marie Curie funded project to provide a suite of training for practitioners to increase cultural sensitivity and competence.



As well as delivering and developing our expert end-of-life care and symptom management services, we continue to focus on reaching more families in their homes and local communities.

It's early days and there is still much more work to do. We will keep you up to date as we continue to develop our services for children and families.

Donate



Dreams come true at COMIC CON!

The Tŷ Hafan Youth Board was approached to see if they would like their very own stall at Comic Con in Barry this year. Of course, this was a dream come true for lots of the young people who are big fans of this ever-popular convention! The young people who went along had a fantastic time – and Emily, who was dressed as Harley Quinn, even took home a prize for her costume!



Emily dressed as Harley Quinn



Seth and Reggie



Keep in touch

Stay in the loop with the latest news and developments from our care services.

www.tyhafan.org/latest-news



Scan the QR code to sign up to our mailing list!



Summer service of remembrance

This summer, we held our annual summer service of remembrance. Over 200 people came, including newly bereaved families and families whose children died many years ago. The newly bereaved families were given their pebble engraved with their child's name and the whole service was set off perfectly with beautiful music from Diane, our Music Therapist, and Heather, our Senior Play Practitioner. There were tears, laughs and lots of cwatches, and we're proud that Tŷ Hafan remains a space for families to reflect and remember their children, even decades on.



‘All about me’ by Math

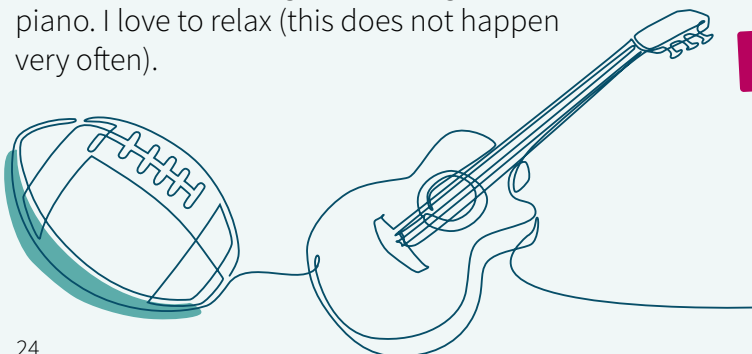


Math

“Hello. My name is Math and I am 9 years old. I am in Year 4 and I’m on the cricket team at my school. I am a fluent Welsh speaker, and I am a member of the Tŷ Hafan Youth Board.”

My big/little brother Nye is older than me but smaller than me. He has severe learning disabilities, is nonverbal and cannot walk, therefore I know a lot about accessibility.

My favorite sports are taekwondo, fencing, rugby, cricket and swimming, and I play guitar and piano. I love to relax (this does not happen very often).



The Youth Board is important to me because I can express the feelings I never thought I could, and I always know where to find a trusted adult. We’ve been on accessibility tours to Cardiff Museum and St. Fagans, and we’re planning to go to the Principality Stadium soon. It’s surprising how many accessibility improvements can be made.



Math and members of the Youth Board at the National Museum Cardiff

My favorite foods are pizza (fresh from a pizza oven), burgers, chips and fajitas. My brother, on the other hand, enjoys yoghurt.

I love swimming and so does my brother. I love tobogganing, white water rafting, go karting and playing with my friends.

My top favorite books are The Trials of Apollo by Percy Jackson. I like Greek and Roman mythology which makes those books so much more interesting.

Keep in touch with us!

Do you want to be the first to hear about our latest news, events and stories from the heart of our work in the hospice and the community? Sign up to our mailing list!

Sign up: www.tyhafan.org/hear-from-us

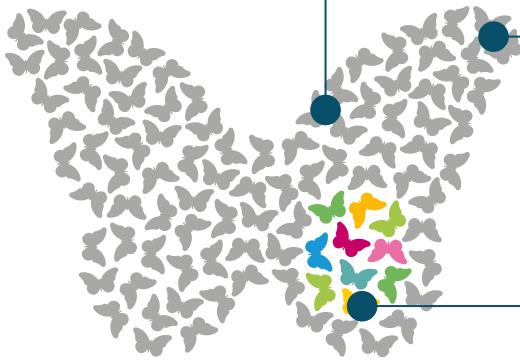


Tŷ Hafan in Numbers



Of the families in Wales who live with the unimaginable reality that their child's life will be short, a shocking **90%** currently do so without the support they need.

That's over **3,000 families** who could benefit from your support.



We only have enough funds to support **1 in 10** of the families who desperately need us.

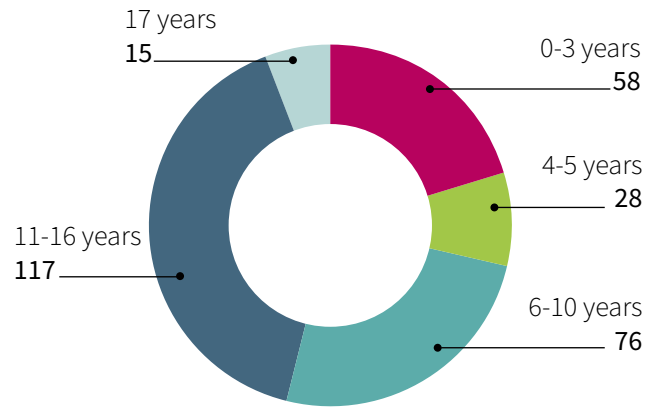


We receive just **14%** of our costs directly from Welsh Government.



Thanks to the generosity of our supporters, there is **no cost** to children and families in need to access Tŷ Hafan.

Current age of children in care*



*not including transition support to adult services



Average age at referral 2019 - 2024



Children who died 2019 - 2024



Number of referrals 2019 - 2024



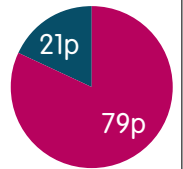
Nights of end-of-life care provided 2019 - 2024

Running costs of care

Annual running costs of care:



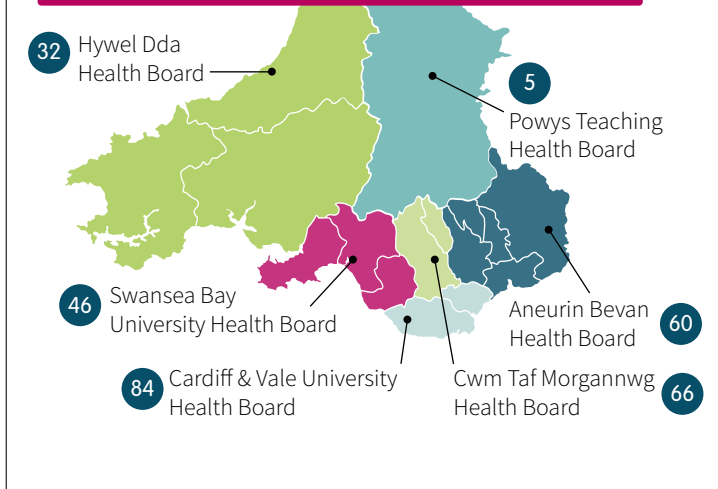
79p in every pound of income contributes to care. Costs incurred in the operation of commercial activities are excluded.



Daily cost of care:



Children currently supported in each health board area



For every **£1** we spend on fundraising, we raise **£15**



Your donations count



£25

could pay for an hour of care from a nurse



£1,500

could pay for a specialist mattress

£100

could pay for an inclusive music, movement and sensory class

pays for medicines for a year

£2,500



£500

funds uniforms for 10 nurses

£3,100



could give a family a weekend of care at our hospice, including food and drink, play and nursing care

£1,350

could pay for a week of food for families staying at the hospice

Treorchy Male Choir and
Treorchy Comprehensive School
Choir kick off Christmas
with a concert on
Sunday 1st December



With special guest
Callum Scott Howells

BBC Hoddinott Hall,
Wales Millennium Centre, Cardiff

All proceeds go to Tŷ Hafan Children's Hospice
£30 per ticket

Get tickets online:

www.tyhafan.org/events/christmas-concert

SCAN ME



Tŷ Hafan



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WALES MILLENNIUM CENTRE

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