

### Message from Maria



Dear All,

Welcome to your Autumn/Winter 2022 edition of Cwtch. I hope you and yours had an enjoyable summer.

Just months after celebrating her Platinum Jubilee, we were saddened by the loss of Her Majesty Queen Elizabeth II. On behalf of the entire Tŷ Hafan family, I sent a note of our deepest condolences to His Majesty King Charles III, our loyal patron since 2001, on the death of his beloved mother. Our thoughts and prayers remain with His Majesty, The Queen Consort and members of the wider Royal Family.

Grief and loss, love and living are the themes of Rose's story which is at the heart of our upcoming fundraising campaign.

Parents Andrew and Catherine Jeans talk about the incredible support Tŷ Hafan gave them, their son Oliver [and their extended family] when Rose, their beautiful baby daughter, was diagnosed with inoperable cancer – which so cruelly claimed her life just two days after her first birthday.

Catherine told us: "We are the unlucky, lucky ones. How do you make that decision where to take your child to die? ... In hospital it's noisy, it's chaotic and very clinical. Tŷ Hafan is a home-from-home environment. Everyone matters.

#### "If Tŷ Hafan wasn't there for us, I don't know what we would have done."

You can read more about Rose's story on page 7. On page 4, you will find information on different ways you can support us to keep on providing end-of-life care for children like Rose and her grieving family, helping them to create precious memories and to live again after the loss of their beloved child. As Her Majesty famously said during the pandemic: "Grief is the price we pay for love."

Finally, you may have seen media coverage about how the cost-of-living crisis is impacting our charity, in particular, with huge rises in our energy bills. No doubt this awful crisis is impacting you, too. We hope you can stay positive.

As always, we remain resolute in our commitment to be there for the children and families who need us, and we cannot do this without you. Thank you for your unwavering support.

Do take care,

Maria Timon Samra Chief Executive, Tŷ Hafan Children's Hospice

#### Contents

Message from Maria	02
Rising costs	03
Shopping sustainably and for less	03
Spotlight on community fundraisers	04
News from the hospice	05
Sending best wishes to our King and patron	05
End-of-life care in a home-from-home	06
Rose's story	07
A day in the life of a hospice nurse	08
Volunteering with Tŷ Hafan	09
Play our lottery!	09
Tŷ Hafan in numbers	10
Business to business: work with us	11
Where your donations go	12
A festive Welsh musical treat!	14

#### Connect with us. .

There's a number of ways to keep in touch with us at **Tŷ Hafan**:



www.tyhafan.org



supportercare@tyhafan.org



029 2053 2255







## **Rising costs**

With the huge impact of the cost-of-living crisis on all areas of our work, we need your help more than ever. You might have seen on the news that our energy bills were set to go from £100,000 to £600,000 per year. Now, set to be around £400,000 per year (for the next six months), we are in an even more financially challenging situation than we faced during the COVID-19 pandemic.

Demand for our services is increasing, but we're losing donations because many people simply can't afford to give to us right now. Tŷ Hafan's donations from individuals have dropped by 50% compared to last year.

Plus, with energy prices dramatically increasing, the essential specialist equipment that we use in the hospice is becoming more and more expensive to run.

We worked hard to share how the cost of living crisis is affecting us in the media, including TV, radio and online coverage from BBC Wales, a live broadcast from the hospice with Good Morning Britain, The Jeremy Vine Show on BBC Radio 2 and we were even mentioned on Newsnight.

We've had lots more radio coverage, too and we were also on Newyddion and BBC Cymru Fyw. Here's a big thank you to Alex and Felix, Jayde and Savanah-Bleu and Bridget and Elain for supporting us in our media outreach.

Of course, we're very grateful to be able to share our story in this way. We're so grateful for the generosity of our supporters which is crucial in helping us to make it through this national crisis.





Top: Alex and Felix on Good Morning Britain Above: Jayde and Savanah-Bleu being interviewed for BBC Wales



Make and Mend workshop in the Penarth Tŷ Hafan store

## Shop sustainably and for less

Choosing to buy pre-loved items instead of brand new reduces landfill and CO<sub>2</sub> emissions, all while keeping your wallet healthier and supporting a great cause.

That's why we're challenging you to do this year's Christmas shopping – even just some of it! - in charity shops. And if you're having a pre-Christmas clear out, we know how much our charity shops will appreciate your donations ahead of the busy retail season.

Taking on the challenge? We'd love to see your photos! You can share photos of what you've bought with us on social media by using the hashtag #shoptyhafan.

We have 19 Tŷ Hafan shops across Wales where you can buy quality pre-loved items at just a fraction of the price of buying new.

Our shops receive around **1,800 bags** of donations each week and we've sold over **200,000 items of clothing**, **17,000 pairs of shoes**, and **14,000 handbags** in the past year. That's keeping **200,000 kg of clothing** out of landfill in just a year!

But eco-friendly fashion isn't just for Christmas time! This Sustainable Fashion Week, the Tŷ Hafan team hosted a Make and Mend workshop in the Penarth Tŷ Hafan store, teaching people how to repair and embellish old clothing, rather than binning them!



Find your nearest Tŷ Hafan store, go to www.tyhafan.org/find-your-local-shop

# Spotlight on... community fundraisers

It's inspiring to see how creative our superstar supporters are when they fundraise for us! In the past few months, we've been lucky enough to have fundraising support in all kinds of imaginative ways.

Henry Hales from Porthcawl drove to Land's End in his classic car and raised a very impressive £600 for Tŷ Hafan. Merle Davies – a much-loved member of the Tŷ Hafan hospice family – was sponsored to not eat meat for a month and raised £300!

Ann Knight from Llantwit Major hosted a Japanese open garden and received £540 in donations for our services. And Claire Drakeley's daughters, another wonderful family that we've supported, got their heads together and raised £602.08 in memory of their beloved brother Milo by bravely cutting their hair.

#### And that's just the tip of the iceberg!

We appreciate the kindness of everyone who donates to us and there are so many ways you can raise money, whether that's a bake sale, an open mic night or anything in between!

#### Get in touch...

Our fundraising team will be happy to help you, too. Get in touch with us by calling us on **029 2053 2255** or emailing us at **supportercare@tyhafan.org** and we'll make sure you have everything you need to get off to a flying start.



Henry Hales drove all the way to Land's End in his classic car in support of Tŷ Hafan!



Ann Knight's open Japanese garden raised £540!



The Drakeley sisters sporting their new haircuts – you look great, girls!

#### **Ways to Support Us**

- Set up a regular donation
  Donating to Tŷ Hafan monthly, no
  matter how big or small the amount,
  gives us a reliable income.
- 2 Include a gift in your will
  You can include a donation to
  Tŷ Hafan in your will to provide
  essential care for the families we help.
- 3 Play our lottery

You can play our Crackerjackpot lottery for £1 per week for the chance to win a top prize of £2,000, with all proceeds going to Tŷ Hafan.

4 Shop Tŷ Hafan

Support us by shopping at or donating items to one of our Tŷ Hafan charity shops across Wales.

5 Fundraise

Whether it's with your colleagues or in the community, setting up a fundraising event is a superb way to raise money for Tŷ Hafan.

Volunteer

We have many volunteering opportunities available at our Tŷ Hafan charity shops, in the hospice, and more.



The Den

### **News** from the hospice

There are always marvellous things going on at the Tŷ Hafan hospice. Here's the latest news...

#### Service of Remembrance

It was heart-warming to welcome families back for our first face-to-face memorial service in 2 years. Our summer *Service of Remembrance* took place in June and gave bereaved families a chance to come together while we remembered their children. This year we had a face-to-face service and a virtual one!

#### The Den

The Den is now fully furnished! The Den is an epic area for the young people who visit Tŷ Hafan. It's a better suited space for their needs than the child-focused hospice environment we have for younger children.

The Den provides room to chill out, watch films, play video games, and more. Plus, the young people we support have been getting creative by helping to design the outdoor space... might there be a pizza oven and funky lighting coming soon?

#### Stay and Play Hubs

Our community van has been busy travelling up and down the M4 taking play, therapies and family support into the community. These *Stay and Play* hubs are very popular with the families we help and give them the Tŷ Hafan experience closer to home.

There are eight *Stay and Play* hubs, with more to come over the next year or so. Families can come along with their children for lots of messy play, storytelling, complementary therapy, music making and catch-ups with staff and friends.

Not only are these *Stay and Play* hubs great for little ones, they're also an opportunity for families to share stories, problems and solutions.

Flip to **page 8** to read all about a day in the life of a Tŷ Hafan hospice nurse



## Sending our best wishes to our King and patron

We would like to extend our sincere condolences to our patron, King Charles III, the Queen Consort and the wider Royal Family on the passing of Queen Elizabeth II.

The Queen was a devoted servant to the United Kingdom and the Commonwealth throughout her 70 years on the throne and we are so grateful to Her Majesty for her steady, dignified and compassionate reign.

We send all good wishes to our King and Patron in his new position as Head of State.



We're so proud of Seth Burke who met King Charles and the Queen Consort at the Senedd as part of his role as Welsh Youth Parliament Member. Seth has been using Tŷ Hafan's services for over 5 years. He is the first wheelchair user in the Senedd's adult or youth parliaments and is the first Member with Duchenne Muscular Dystrophy.

Seth described this fantastic experience: "The King had to bend down to talk to me because I'm in a wheelchair. This I found really funny, as in all the photos he looks like he's bowing to me! He shook my hand and asked me if I was still in school.

"Next, I met the Queen Consort and she was really nice, too. She asked if I was bunking off school and said she "wouldn't tell" if I was. I said, "Thank you - there are billions of cameras looking at us though," and she laughed about that."

Well done for making history, Seth!





## End-of-life care in a home-from-home

Perhaps from an early age, we feel unable to talk about dying. For some, this might have even been discouraged. But as sensitive as it is, we must talk about this. Between April and September this year, 14 children have died at Tŷ Hafan. In that time, and throughout all the years we've been there for families, we have worked tirelessly to make the most out of every moment of a child's life. It's our purpose.

When the time comes for a child to die, we're with our families every step of the way, providing emotional and practical help whenever and however it's needed.

There are many myths surrounding what end-of-life and bereavement care is like. In truth, *every experience is unique*.

#### End-of-life care at Tŷ Hafan

End-of-life care at Tŷ Hafan starts when we meet the family for the first time. While families might worry about their child dying at home, most of the families we work with choose not to see their child die in hospital. Being at Tŷ Hafan offers them balance – a home-from-home – with expertise from palliative care professionals.

Specialists and Family Support Practitioners meet with the family to get to know their wishes inside out. Working with healthcare professionals in the NHS, we put together and deliver individual care plans.

Family Support Practitioners give families quality psychological and emotional care to help them cope with the complex and consuming feelings that death and bereavement can bring.



Rose Jeans



Andrew and Catherine Jeans

When the time of passing comes to a child, we're here, making the process as comfortable and comforting as possible with medical support like pain management and compassionate removal of breathing support (known as extubation). Families can have as much or as little privacy and emotional support they need during this difficult time.

Accommodation, facilities and specialist equipment are all available at our hospice so that a family – and extended family - can stay with their child before and after they've died.

We offer practical help to take some of the pressure from the family's shoulders. We can register their child's death, help with informing other relatives and friends of their passing and assist with funeral arrangements.

#### Tŷ Hafan's support doesn't end when a child dies

Our relationship with families continues after a child has died. We offer access to support groups that can be used whenever they are needed, and for however long they are needed. Access to the hospice gardens and our memorial space is also available for quiet contemplation and reflection. We are always here for a cuppa and a chat. Always.

#### Find out more...

about the types of care we offer families, go to: www.tyhafan.org/how-we-care

## Rose's story

The Jeans family have experienced end-of-life care at Tŷ Hafan.

Andrew and Catherine Jeans' baby daughter, Rose, died of Atypical Teratoid Rhabdoid Tumour (ATRT) just days after her first birthday.

"If Tŷ Hafan wasn't there for us, I just don't know what we would have done. Tŷ Hafan gave us privacy. But we could still have family around us. Tŷ Hafan enabled them all to be there for us. It's a home from home environment. Everyone matters. In hospital it's different, it's noisy, it's chaotic and very clinical," Catherine tells us.

### It has to be an option for someone. Tŷ Hafan has to be there. 9 Catherine Jeans

"What does Tŷ Hafan give you? Moments you can share. Camaraderie. Relationships in most difficult times. We are the unlucky lucky ones. How do you make that decision where to take your child to die?

"For us, we did not want to go home for Rose to die at home because you've got to live in that house afterwards.

"What Tŷ Hafan gives you is priceless. We would not have provided what Tŷ Hafan did for our daughter. The care and love Tŷ Hafan showed was amazing. We could come together for Rose's first birthday. Oliver [Andrew and Catherine's son] was entertained which meant that we could focus on Rose.

"Oliver will be 10 in December and he has had to go through so much in his life already. But thanks to Tŷ Hafan, he's coming on amazing! He's had counselling to help him cope with the death of his baby sister and everything we've had to go through.



Oliver Jeans

"He's also a member of Tŷ Hafan's Super Sibs group and he loves that because he's with other children who are going through similar things. He doesn't have to say anything, if he doesn't want to. They just know. And it's the same for us. We're in every group. We know that you are there if we ever need anything."

#### **Donate and support**

Without your donations, we simply couldn't do what we do. Give children with life-shortening conditions the end-of-life care they deserve by supporting us with donations, fundraising or volunteering (go to page 4 of this issue of *Cwtch* to find out more).

#### Did you know...?

Memory making is a big part of end-of-life care at Tŷ Hafan. It can include all kinds of activities, like exciting experiences, decorating the child's room with their favourite things, taking photographs, making handprints and hand casts and creating artwork together.

#### Did you know...?

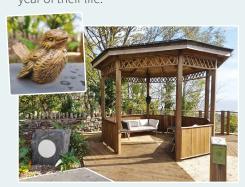
Did you know we have seven therapeutic support groups, such as our Super Sibs club?

These groups give families space to talk to others who understand their situation.

#### Did you know...?

Did you know that we remember children with our Birdsong Project?

When a child dies at Tŷ Hafan, their name is translated into birdsong (the song of the bird that sings the loudest during the month they were born). The birdsong is followed by a second of silence for each year of their life.



Families can listen to the birdsongs in a very peaceful spot in our garden.

#### Did you know...?

Did you know that we give bereaved families remembrance pebbles?

We offer every family that has lost a child a pebble carved with their child's name. They can take it home or keep it in our beautiful memorial garden.

#### Did you know...?

Did you know that we hold two memorial services every year?

Twice a year, families of children who've passed away at Tŷ Hafan are invited to a remembrance service: a summer remembrance service and a candle service in the winter.



## A day in the life of. . . a hospice nurse

It goes without saying that we couldn't give families the standard of care that we do without our brilliant team at Tŷ Hafan Children's Hospice. But what does a day in their life actually look like? It might be different to how you imagine it. We spoke to one of our outstanding team members, Carly Davies, who is a Learning Disability Nurse (RNLD), to find out.



"When we start our shift, we're told which child and family we're going to be to looking after that day - the care and support we provide hugely varies from child to child, depending on their needs.

"For me, it's not just about meeting the child's clinical needs, although that's the priority. It's about making their stay here as enjoyable as possible. It's often a mixture of accessing the Play Team and the services they offer and using my own initiative to engage the child in their favourite activities.

"That could be all kinds of different things. The excellent Play Team organise a wide range of activities like crafts, walks, day trips and even story massage. Story massage is an activity that I often support the Play Team with. It's where they read stories to the children, but the story has a massage incorporated into it, and I do the massage.

"I come from a theatre background, so I try to incorporate that as much as possible by singing with the children... but sometimes they tell me to stop! I think when people think of hospice care, they think if it as being really sad. And it can be. But there are lots of aspects of Tŷ Hafan that are so uplifting.

"For example, before I started, I didn't know there was a Play Team. It offers families that little bit more.



Carly Davies - Learning Disability Nurse

Something I think is amazing is the equipment in the music room that enables children who struggle with movement to use their eyes to make music! So, even children with very limited mobility can still be involved in exciting activities.

"Of course, there are challenges that come with working in a children's hospice. It can be a hard job and it can be emotionally exhausting, but it's really rewarding. For a family to allow you to be a part of their journey, for me, is a great honour. It's really special.

"By far the best part of my job is getting to know the children and building a rapport with them and their families. There's nothing better than engaging a child in an activity they love and they're smiling and they're happy."

#### Thank you for sharing your time with us Carly.

#### Join Team Tŷ Hafan!

Just some of the benefits our care staff can enjoy are:

- 30 days holiday (+ more with service) + Bank Holidays
- Unsociable hours payments & overtime opportunities
- Professional development & training opportunities
- 5% employer pension contribution or the ability to continue with NHS pension
- Employee Assistance Programme & formal clinical supervision
- Cycle to work & shopping discount schemes
- On-site free parking & subsidised meals

Tŷ Hafan is always on the lookout for hospice care staff, so if you'd like to join our team, please get in touch!
Email us at careers@tyhafan.org or visit the
Job Opportunities page on our website
www.tyhafan.org/job-opportunities.





## Volunteering with Tŷ Hafan

These are the volunteering opportunities we have up for grabs...



#### Volunteer Retail Assistant (Under 18)

Are you 16 or 17 and want to volunteer in your local community? This role gives you a mix of experiences, including merchandising and pricing items, speaking to people from all different backgrounds, and growing your skills.

#### Retail Stockroom Volunteer

You can become a Retail Stockroom Volunteer at any of our shops, helping with stock, merchandising and more.

#### Till & Customer Service Volunteer

You can become a Till & Customer Service Volunteer at any of our shops, helping customers, increasing sales and more.

#### Volunteer Kitchen Assistant

Good food is central to the care we provide, from catering for specialist dietary needs in the everyday to special occasions, and we're looking for someone to help our kitchen staff. This role is based at the Tŷ Hafan Hospice in Sully.

#### **Crafts Volunteer**

At our crafty workshop based in our Head Office in Sully, Crafts Volunteers help to make high-quality products to sell on our Handcrafted by Tŷ Hafan Etsy shop.

#### Volunteer Collection Box Agent

The Volunteer Collection Box Agent makes sure the collection boxes out and about in the community are coordinated and collected. If you can pop to your local shops and centres nearby and help collect boxes, then this role is perfect for you.

#### Volunteer Van Mate

As a Volunteer Van Mate, you will help with delivering and collecting furniture and help our paid van driver in the lifting and moving of furniture items.

#### Volunteer Receptionist

We're looking for friendly and experienced volunteers to join our team of receptionists. We are looking for volunteers who can work from 1 pm - 5 pm on either Monday, Wednesday, Thursday or Friday, or Wednesday 9 am - 1 pm.

#### Volunteer with us

That would be brilliant! Contact Deborah John by email deborah.john@tyhafan.org or over the phone 029 2053 2254 to find out more.

## crackerjackpot

£2,000 top prize

Every Friday you could be our lucky lottery £2,000 Jackpot winner with Crackerjackpot - all in support of Tŷ Hafan!

Just £1 per week to play

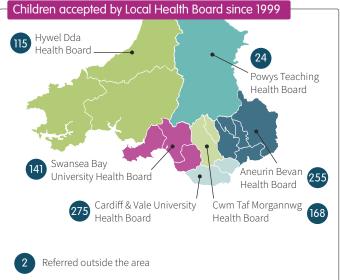
Play now www.tyhafanlottery.co.uk



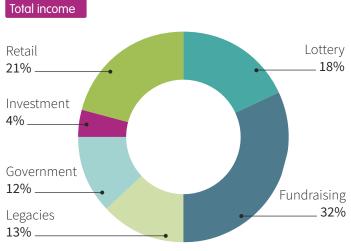
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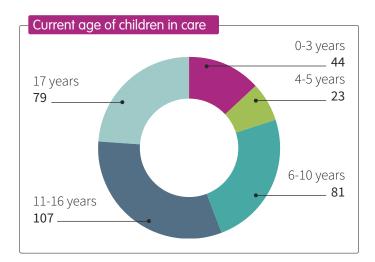
### TŶ HAFAN IN NUMBERS





#### Running costs of care 2021/22 annual running 82p in every pound of income costs of care contributes to care. Costs incurred 82p in the operation of commercial activities are excluded. million daily cost of care







#### (under 1 year of age)

Average age at referral in the last 12 months



Young people who have graduated from children's services April 22 - Sept 22



Children who died April 22 - Sept 22

Number of families accessing bereavement support



Number of families receiving community/family support October 2021 - September 2022



Number of families accessing short-break care



Number of children accessing a crisis care stay in last 12 months

#### Number of lottery plays

crackerjackpot















**Ambassadors** 



Staff







## Business to business: work with us

Your business can help deliver life-changing services for the children who need us, from music therapy and messy play to end-of-life care.



Euro Commercials Mercedes Benz have supplied this wonderful van

The daily cost of Tŷ Hafan's care is £14,727. That's £5.2m each year. It's a huge sum and the heroic businesses that are generous enough to donate to us play a vital role in raising this money. If you'd like to become a corporate supporter of Tŷ Hafan, we'd be delighted to work with you.

#### Why support us?

#### Bespoke opportunities

There's no one-size-fits-all approach to supporting Tŷ Hafan. We'll work with you to find the perfect opportunity for you and your team.

#### Team bonding

Studies show that 67% of workers feel disconnected from their colleagues when they're hybrid or home working. Fundraising can really boost morale and get everyone working as a team again.

#### Reputation building

We'll regularly celebrate your kindness and generosity, helping you reach socially conscious customers, meet your ESG goals and build your reputation.

#### Stay connected

You'll get a dedicated account manager who will make sure you and your team are kept up-to-date with the amazing work your money is doing to help Tŷ Hafan families.

#### Ready to work together?

Get in touch with our Corporate Partnership Team by emailing joinus@tyhafan.org or calling 029 2053 2199.

#### How you can get involved

#### Corporate partnership

When you become a corporate partner, your Tŷ Hafan account manager will work closely with you to create a tailored plan to help you reach your goals and maximise your benefits.

#### Cause-related marketing

Donating a percentage of your profits to Tŷ Hafan promotes your products and services and gives us regular income.

#### Payroll giving

Easy to set up and tax effective, payroll giving is a regular donation that comes straight out of your employees' salaries when they opt-in.

#### Sponsor an event

Raise money and increase your business's visibility by sponsoring a Tŷ Hafan event.

#### **Fundraising**

Fundraising comes in different shapes and sizes. However you choose to fundraise, our team will give you everything you need from advice to publicity materials.

#### **Donate**

Simply give a gift donation through your business.



Nuttall Parker Estate Agents donate £50 of every sale to us



## Where your donations go

£14,727

Could pay for a whole day of expert medical care and support at our hospice for several families.



£11,000

Pays for a **specialist cot**.

£10,000

Provides 24-hour nursing care for a child for a week, giving parents precious time off from being a carer.



£7,000

Gives a family **five days of short break care** at the hospice, helping mum
and dad get some much needed rest.

£4,500

Pays for a specialist hoist.

£1,000

Could pay the costs of the medical supplies used at the hospice for a month.

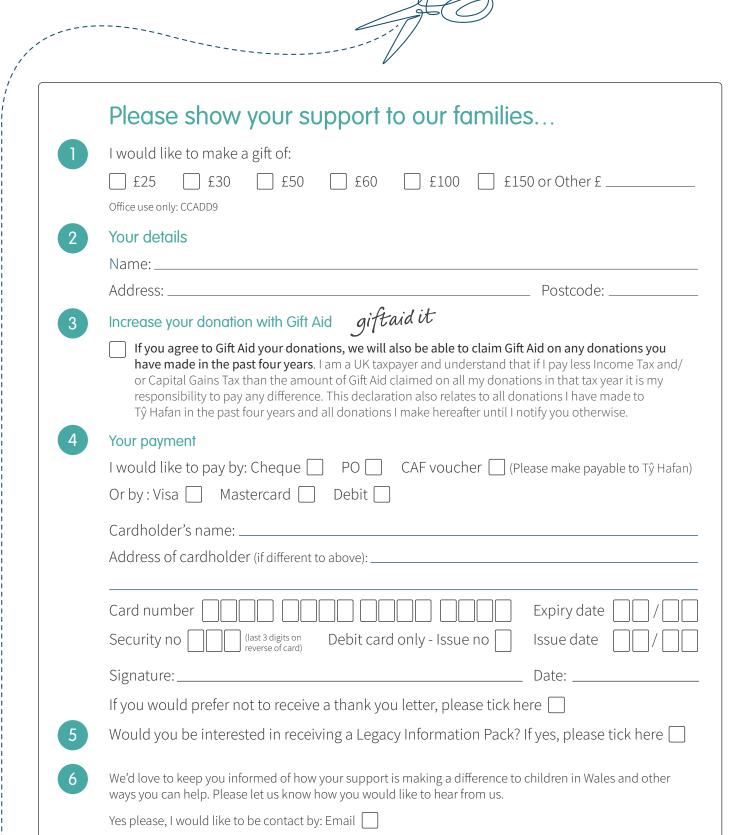


£250

Funds **five hours of music therapy** for a child in their own home.

£50

Pays for **an hour of music therapy**, giving children the chance to make lasting memories together.



You can change your mind at any time by emailing **supportercare@tyhafan.org**We value your support and respect your privacy. We will never sell or share your details a

We value your support and respect your privacy. We will never sell or share your details and promise to keep them safe. For further details on how your data is used and stored, visit www.tyhafan.org/data-protection



My email is: \_\_

## A Festive Welsh Musical Treat!

Treorchy Male Voice Choir & Callum Scott Howells will sing their hearts out in support of Tŷ Hafan

With the nights drawing in and the temperature dropping, the summer days are well and truly behind us.

That means we can look forward to jumpers, twinkling lights and (...is it too early to say it?) Christmas!

Bringing you that festive feeling in support of Tŷ Hafan, the iconic Treorchy Male Voice Choir and Callum Scott Howells are performing at St David's Hall on Tuesday 6th December at 7pm. This family-friendly event will be hosted by our lovely supporter, Steve Speirs.

Treorchy Male Voice Choir has been running for more than a century and is loved for being one of the world's most renowned choral ensembles. Rising star, Callum Scott Howells, has made a name for himself in titles such as *It's a Sin*, *Oliver!* and *Lord of the Flies*.

All proceeds from this festive concert will go to **Tŷ Hafan Children's Hospice**, helping us deliver much-needed care and community services for children with life-shortening conditions and their loved ones in Wales.

#### **Ticket Prices**

Standard Price: £14.00 | £18.00 | £20.00 | £24.00

Under 16s: Half price tickets

Wheelchair user plus one companion: (please contact Box Office on 029 2087 8444)

Stalls seats: £14.00

(Optional £2.00 postage fee)

For further details and to book online, visit www.stdavidshallcardiff.co.uk/whats-on









