

harley's story



carmarthenshire



tŷ hafan

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

Harley, a “cheeky chops” seven-year-old from Llanelli, is definitely one of a kind. He had his first operation on a cystic lung while he was still inside his mum Becca’s tummy. At two days old, he had open surgery to remove most of his left lung. A week later his other lung collapsed then they found a hole in his heart. He has lived his whole life with multiple health issues from having to be tube fed to severe seizures and developmental delay.

It turns out Harley has a number of genetic abnormalities and has been diagnosed with Adenylosuccinase deficiency (ADSL), with symptoms including autistic behaviours, epilepsy, feeding difficulties, hyper mobility and hypotonia (low muscle tone).

ADSL is a progressive disorder and Harley’s condition has developed over time. But while he is at high risk of sudden death through epilepsy, Becca was never sure that they were eligible for support from Tŷ Hafan as she’s never seen him as life-limited. However, it was another Tŷ Hafan parent she knew who suggested that they come to see us, especially as symptom management is provided at the hospice.

The timing was good as the family were going through a very difficult period with Harley, who was in a lot of pain due to stomach issues, vomiting and reflux. Doctors had yet to find the right medication balance which meant he was often very drowsy, but still had real difficulty sleeping. His autistic tendencies also meant that he would lash out towards mum, dad and sister Bailey, and he had also been self-harming from a very young age by clawing and punching away at himself.

So Becca and Harley came for their first visit in summer 2020 amid all the chaos of the Covid-19 pandemic. They had been on the waiting list for local respite and were at a crossroads with carers as they needed to shield. With nobody able to babysit, the whole family was at breaking point.

Visiting Tŷ Hafan meant that Becca could stay with Harley (she wasn’t ready to leave him with others yet) but would have the assistance of the nurses and care teams. It also meant that, for five nights, Harley was observed, allowing staff to see exactly how he was faring under his medications and routines.

Becca said: “I never thought Tŷ Hafan was right for us because I thought it was for end of life only and that wasn’t us. But when we went to the hospice to stay, it gave the doctors a chance to see what was going on. Harley didn’t eat or drink for a week, but it meant that they knew what they were dealing with and it helped us get the referral we needed.

“He is incredibly shy, but Harley is very funny and a typical boy really. He can

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be so direct with you; he'll always say what he really thinks. He loves to play Roblox and on his X-Box, they are his favourites, but he won't go to bed without giving Elmo a kiss every night. He loves Christmas time, obviously because of Santa and he gets so excited when he sees him, but mostly because of the lights. He loves lights. We try to go to Blackpool every year to see the lights there, but we couldn't this time because of Covid. He loves trams and buses, arcades with the sounds and colours.

"When we go for walks, he gives us a running commentary and he gets really into things. He's so observant and will spot all the NHS rainbows and point each and every one out. Same with dogs and other animals, he loves to tell us about the things he spots.

"We have good and bad days. He loves to sing and dance, he would sing Mariah Carey all the time over Christmas. But it's been really hard for us all. He can be quite violent towards us and now he is seven and he is getting bigger, it can be quite hard, even for my husband. It takes its toll because I sleep in with Harley, so me and my husband sleep separately.

"Bailey, Harley's sister, is four now and she is great with him. She absolutely doesn't get enough credit for what she does for him and what she has to deal with. Harley needs to use a feeding tube and she could get quite distressed seeing him struggling, she worries that he is being hurt. We had to sit her down and talk her through it, so she knows how important it is. But she also gets him, she understands that he needs our



attention a lot of the time and they get on so well. It's so hard to spend quality time with just her as Harley needs so much attention. We try to make sure there is time just for her, but it might just be going to school or her groups where she gets our full attention."

"I spoke to her teacher about it because I'm so proud of how she deals with everything and they didn't realise, because Harley goes to a different school and she just takes it in her stride, but she deserves so much credit. I think the sibling support at Tŷ Hafan will be great for her."

Only Harley and Becca have been to Tŷ Hafan so far, but the whole family is excited to be able to visit and see what it is like for themselves. In the meantime, family support worker Kirsty is on hand to check in and provide support whenever needed:

"Kirsty is always available at the end of the phone or on Zoom if we need her and she probably checks in every couple of months to make sure we are doing ok. Covid is a prison for us really. Harley can't even go outside like he could before, but it makes us worried to as well. We've really liked following what they have been putting online for us. When we visited the hospice, we were watching The Greatest Showman, one of Harley's favourites. Heather came out with her guitar and said: 'I know that song' and serenaded him. He was fascinated and sang and played along. Now when he sees her on Facebook, he is captivated by her. The others too, but Heather is his favourite.



I saw other children and was amazed at how the staff were with the kids. I've never met such nice people.

"But people don't get to see this side of him because he is so shy, even at school. So I try to take as many videos as I can of him to show people the real Harley.

"We have too much to pack to go away for long, so holidays are impossible. Going to Tŷ Hafan is different because they are used to it and it's normal for them. It makes it easy to fit in there. You can talk to people about things, but to meet other parents in the same position as you is good as you feel less self-conscious with a Tŷ Hafan group.

"All the staff were amazing. I wasn't ready to leave Harley, I'm still not, so I stayed with him the whole time, but I saw other children and was amazed at how the staff were with the kids. I've never met such nice people. The one time I left him was to go for a shower for an hour. I've never done that before, but I felt able to as I knew he was being looked after.

"I don't like 'terminal' because that's not where we are yet. Our doctor is very straight talking, which I actually like, but I'm not sure if he thinks I understand what he is telling me sometimes

Tŷ Hafan takes its support to wherever it is needed: at home, at school or in hospital. We do this completely free of charge for families in Wales that need us. Please help us continue to be there for children with life-limiting conditions and their families, so they can make the most of the precious time they have left together.

with his epilepsy. I do, but that's not where we are yet.

"When I look at him, I wonder how long we will have you for, but I don't want that fear to rob us of today."

Tŷ Hafan is very different to what people often think of when they hear the word 'hospice'. It has been described as "a club that nobody wants to be part of", but it's a club there to provide the support its members' need.

We are reliant on the support of the people of Wales so that we can continue to be this source of comfort and care to the families who need us.

Becca added: "I've done quite a lot of fundraising locally for the special school, as well as local care homes and community causes, but I want to take part in the Tŷ Hafan lottery, Crackerjackpot. There are lots of ways to support the charity, even in a pandemic, and when I saw what government funding Tŷ Hafan had, I realised how important fundraising is to them. They help our family so I like to be able to give back when I can."

thank you!
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