

felix's story



vale of glamorgan



tŷ hafan

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



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When Dan and Alex’s baby son Felix was just a few months old, his parents received the devastating news that their little boy had a life-limiting condition and would never walk, talk or even live past infancy.

The joy and hope that most brand new parents experience turned to despair as they contemplated their future and the dark times that were ahead of them.

“I was completely broken”, said Dan.

“As a parent, you’d do anything to protect your child, yet here I was, less than 3 months in, facing a situation that would strip my child away from me and there was nothing I could do about it. I felt like I’d failed my family and worst of all, my son. The aspirations of seeing my son graduate from university, get married or watch him get to play for his country, had been snatched away from us, and instead, we were facing a very different future”.

“Felix was our first child and we were getting ready for parenthood. What we weren’t really expecting was to become doctors, nurses, carers – everything for Felix – at the same time”.

It was at this point that the family was referred to Tŷ Hafan.

“I’ll admit that despite having raised funds for Tŷ Hafan before that time, I was still a little unsure about what they did. My initial thoughts were consumed by bleak images of sick children, living out their final days. But Tŷ Hafan is anything but bleak”, Dan said.

“The energy, vibrancy and friendly atmosphere make it a place you enjoy going to and being around other families in a similar situation. It helps remove any stigma around what you’re dealing with, which is vital early on”.

Felix’s condition is called Lissencephaly Miller-Dieker which means that on a daily basis, he has seizures. He’s peg fed through a tube directly into his stomach and has frequent pneumonia. However, despite his initial prognosis, Felix is now 6 years old and doing well. He’s a beautiful,

happy, loving little boy and he loves his visits to Tŷ Hafan, where his parents say he gets ‘spoiled rotten’ by the nurses who know him so well.

“Having a poorly child means having a lot of pressure and rarely being able to ever get a break from it because you become the main carer”, said Alex.

“Felix’s needs are complex and change all the time and we do get to a point where things just become very, very hard. When we do get to that point, it’s great to have Tŷ Hafan there to be able to take that responsibility away for just a few days, so we can do very ordinary things like have a full night’s sleep or maybe just watch a TV programme or a film without any of Felix’s alarms going off in the house. We can take a break from that stress and strain and have a bit of time just to be husband and wife or mum and dad to Felix and our daughter Lottie”.

Dan and Alex are members of the Tŷ Hafan mums’ and dads’ support groups – two separate networks of parents of children who have used or are using Tŷ Hafan.

Dan explained how the group helps him. “We are all in the same situation, we all share that bond. It’s not something that has to be talked about – that’s the difference between that and when you’re out with people who are just having normal lives. With the dads’ group, everyone knows exactly what it’s like; you don’t have to explain anything. We can talk freely, we can talk about the hardships, the highs and the lows of the situation – everyone just gets it”.

Dan continued: “The help and support Tŷ Hafan has provided my family over the years has been invaluable to us. From respite care, to providing a place to be able to chat with other families in the same position, their support has helped us so much”.

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 life-limited children and their families, so they can make the most of the precious time they have left together.

For more information visit www.tyhafan.org or call 029 2053 2199.

thank you!
diolch!



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