News from the Ark

Noah's Ark
Children's Hospital Charity
Elusen Ysbyty Plant

Creating brighter todays and better tomorrows for young patients at our nation's children's hospital.

Spring/Summer 2026

Helping Lilah to find her way back

The Noah's Ark Charity Wellbeing Service is funded by people like you through our *Here for You* and *Sparkle Appeals*. The team consists of counsellors, sparkle co-ordinators and a music therapist and together, they are there for children and families when they need it most. For Lilah and her mum Lindsay, that support brought comfort, connection and moments of light during the darkest of times.

Lilah from Penrhiwceiber was first admitted to the Noah's Ark Children's Hospital for Wales with diabetic ketoacidosis last September. Ten days later she developed a blood clot and a brain bleed and was moved to the paediatric critical care unit (PCCU). Though worse on the left side, the bleed had affected the whole of Lilah's brain, meaning that she wasn't able to move or breathe unaided. There was also damage to the parts of her brain which controls speech and understanding. Mum, Lindsay, was told to prepare for the fact that the little girl she had known could be gone forever.

After three long weeks, Lilah was finally considered stable enough to move to Owl Ward. For Lindsay, this is when the reality of their new situation hit.

> **"At this point, Lilah was still completely unresponsive. She couldn't move any part of her body, including her eyes, and there was absolutely no sign that she recognised or was responding to me or anything else. The gravity of the situation hit all at once and I just collapsed emotionally."**

It was at this point that Linsday was introduced to the charity's ward counsellor, Shareefa. Lindsay continued:

> **"I truly believe that there are people who are supposed to cross your path in life. Shareefa helped pick me up off the ground, both literally and emotionally, on that day. She's been there, providing me with the support I've needed, at each point ever since. Being in hospital with a child facing a life-changing diagnosis while being away from everything and everyone else I knew, was the loneliest feeling I'd ever had. It felt like I didn't have anyone to turn to. But then, when I met Shareefa, I did."**

Tŷ Hafan
CHILDREN'S HOSPICE
HOSBIS I BLANT
Hayes Road
Sully
CF64 5XX
Tel: 029 2053 2255

Dear Friend

May 2026

Winnie was only 14 months old when she died.

We were in intensive care when a doctor first mentioned Tŷ Hafan to us. My husband, Anton, didn't know what it was, but I did. 'Tŷ Hafan's a hospice,' I thought. 'No way is Winnie ever going there.'

Winnie was a bit of a shock, to be honest. She wasn't planned – she was a happy accident. We already had two boys, Arthur and Henry, when Winnie arrived our family was complete. I was so happy. Now I had a daughter I could have that special bond that I have with my mother.

She was a delicate little thing, not like her brothers. The boys loved their food, but Winnie wasn't a good feeder at all. But she was happy, a contented baby with big blue eyes and blonde hair. After a while, the Health Visitor said she was a little bit behind. But nothing that we thought would end up like this.

Winnie started to get quiet. She was eight months old and in hospital with tummy problems. But then the doctors told us they'd found a white mass on her brain. They told me and Anton to go home and spend as much time as possible with Winnie as they didn't know how much time she had left.

I just couldn't – and wouldn't – believe it.

We had Winnie home for four weeks. Our routine was full on but I was prepared to do anything for her. She loved Wotsits and Poppadums and could wrap us all around her little finger! And she idolised her big brothers.

But she went bad again, went back to intensive care and a few weeks later another scan showed the mass had grown. The doctors told us Winnie had Alexander Disease, and she wasn't going to get better.

That was the moment of realisation for us. Nobody can prepare you for the news that your child is going to die.

Without Tŷ Hafan it would have been awful. The nurses at the hospital are amazing, I know they would have tried their best for Winnie. But everything in hospital is so clinical, it just wasn't want we wanted for Winnie in her final days and hours.

No family should have to face what we went through alone but, for every family like mine, there are nine other families in Wales who have nowhere to turn.

Will you give a donation of £25 to help other families like mine?