

# elain's story



**tŷ hafan**

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

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Elain loves Tŷ Hafan. They are a lifeline for us and help us create special memories which we'll cherish forever.

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aberystwyth





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**Little Elain James was referred to Tŷ Hafan in January 2011. Elain was antenatally diagnosed with congenital heart disease, but it wasn't until she was born that her family knew the full extent of her illness.**

**Tests revealed Elain had multiple, complicated heart conditions and a rare genetic disorder called 22q11.2 Deletion Syndrome. She also has a permanent feeding tube attached to her stomach.**

Five-year-old Elain underwent heart surgery at just three months old and spent five months in hospital. Elain now has a good quality of life, but sadly, it is only a matter of time before her condition deteriorates.

Her mum, Bridget, said: "Her heart condition is repairable in many cases but unfortunately for us, not in hers. It's very rare to have a child with a heart condition that can't be fixed."

Caring for a child like Elain can, and does, affect all aspects of family life.

Tŷ Hafan provides vital support for the whole family, including their baby daughter, Martha, offering short break care at the hospice, a listening ear, a shoulder to cry on and vital emotional and practical support for Bridget and Gareth, at their home in Aberystwyth.

Bridget said: "Elain loves Tŷ Hafan. They are a lifeline for us and help us create special memories which we'll cherish forever."

Elain adores relaxing in the charity's hydrotherapy pool and its new desert-island themed adventure playground.

"We are able to relax at Tŷ Hafan and do the normal things that other families may take for granted. It can be difficult at times, but knowing that Tŷ Hafan is there for us is such a comfort," said Bridget.

Not knowing how long they have left with their beautiful daughter means Bridget, 30, and Gareth, 35, want to make every moment count. Bridget added: "We feel extremely lucky that Elain currently has such a great quality of life and is an extremely happy and content little girl.

"We would like to thank Tŷ Hafan for all they do for us and are so grateful they are with us on our journey."

**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](http://www.tyhafan.org) or call 029 2053 2199.**

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