

ABOUT ELLIE

Ellie passed away on 5th January 2012

Photo essay - how Ellie became the inspiration for Ellie's Haven

Ellie was born on 25th January 2005 and is the child of Julie and Nigel Libby. Four years previously, Julie and Nigel had had a little boy called Thomas who sadly passed away when he was only fourteen months old. There's no name for the condition that Thomas died from but it's believed to be linked to the genetics of both Julie and Nigel. The geneticist believed that if they had a baby girl it was more likely that she would not be similarly affected.



When Ellie was born, everything looked fine. She had a sort of bruise on her forehead from a ventouse cup used during delivery, but it disappeared over time. However, it soon became apparent that she had a similar terminal condition to her brother. Within a few weeks, Julie and Nigel knew something was wrong. Ellie had feeding problems, she seemed tired and her neck muscles/head control didn't appear to be developing as they should. An eight-week checkup confirmed their



In her first year of life, she had to be rushed into hospital 33 times. Ellie is shown here with her sister Sophie

Ellie requires around-the-clock care because of the following conditions:

- Global developmental delay
- Laryngomalacia (The soft, immature cartilage of the upper larynx collapsing inwards blocking the windpipe. As a result, Ellie has to breath through a tube inserted into an opening in her throat. She also has to be fed liquids only by another tube into her stomach)
- Seizures and vision impairment



Derriford Hospital didn't have a children's endoscope to investigate Ellie's problems so Nigel and Julie launched an appeal for public donations to pay for one. They were overwhelmed by the response. That got them thinking about raising a lot more money to build a holiday retreat for families with similar problems - the genesis of Ellie's Haven.



Ellie was not expected to live beyond her first birthday but she's turned out to be a real fighter. She celebrated her 5th birthday in January 2010.

Julie and Nigel have had to learn to not be over-protective towards Ellie. At one stage they thought they were the only people that knew how to look after her and were terrified by the prospect of Ellie going to nursery. Now, Ellie goes to school, a special unit at Woodlands School in Plymouth, every weekday.

Ellie catches the bus to school at 8:00 AM and gets back at 4:15 PM, looking tired. Mind you, that's hardly surprising. She has to wake up at 5:30 AM to be ready for the bus. Dressing and sorting out her medical requirements takes an hour, and then feeding her takes another hour.

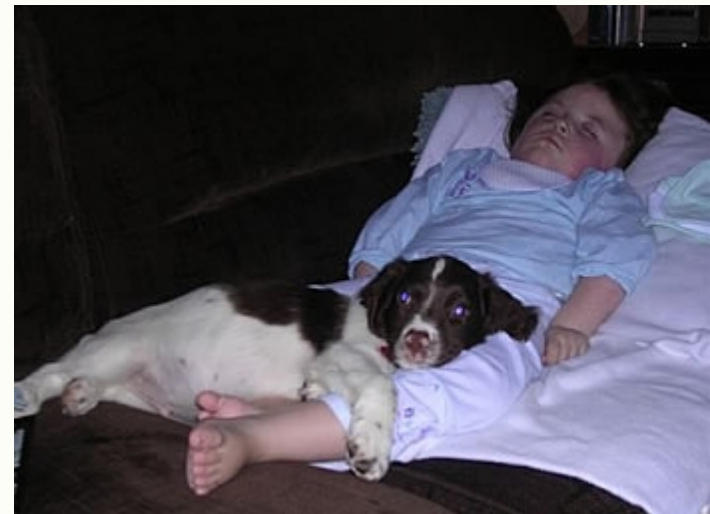
While Ellie is at school, the house feels very empty - she leaves a big void in our lives, says Nigel. Ellie is shown here in the hydrotherapy pool at school



Now for a few photos of Ellie's family:
Ellie, sister Sophie and mum Julie
Ellie and Nigel, her dad



Julie's mum and sister Ellie and Tye, the family dog, when he was a puppy
The point is that Ellie shouldn't be thought of in isolation; she's part of a family that loves her and lives with the consequences and demands of her illness on a daily basis.
That's why whole families with disabled children need relief - the ethos behind Ellie's Haven.



TIMELINE



How It Began

It all started with Derriford Hospital not having a childrens endoscope and needing one to treat Nigel and Julie Libby's severely disabled daughter, Ellie.

Nigel and Julie launched an appeal for public donations to pay for one and were overwhelmed by the response.

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What's Happened Since?

Nov 2007 Ellie's Haven charity founded
Nov 2008 Preliminary design of £1.5M project completed
Nov 2008 Fund raising hits £100,000
June 2009 Fund raising hits £200,000
Sept 2009 Charity shop opened
Jun 2010 Fund raising hits £300,000
Apr 2011 Revised project to cost £700,000
Nov 2011 New strategy of converting existing property agreed
Dec 2011 Fund raising hits £390,000
Jan 2012 Offer accepted for property for conversion
Apr 2012 Planning permission granted for conversion
Sept 2012 Purchase completed of property for conversion
Oct 2014 Sufficient funds raised to start building work
Jan 2015 Building work starts
Sep 2015 Ellie's Haven retreat opens!
Dec 2015 Sensory studio opens!
Oct 2021 Nigel and Julie take a step back from the running of the charity but their daughter, Sophie steps in as General Manager (Maternity Leave).
Jan 2022 After a successful merger, Ellie's Haven becomes part of the Kids In Action family.

What Happens Next?

We are taking bookings for holidays and sensory studio sessions!