



And last November Derian House sent us on a free holiday to one of its brand-new holiday lodges in the Lake District, which was incredible after a difficult two years shielding due to the pandemic.



← Making happy memories with Derian on Holiday

It was wonderful to just relax and forget about reality for a week. We visited a local garden centre and went to the playground. We even invited her grandparents to stay for a night. It was the first time in 17 years they've been able to have an overnight stay with their granddaughter. I'll never forget the look on her face in the morning when she woke up to see them there. Amélie loves animals so they took her to a nearby farm while Lesley and I went out for a meal, just the two of us. It was perfect. We have done lots of fundraising for Derian House over the years because we know there will always be more families like us who need the charity's help. Although care is free for families, it costs £5 million to run services at Derian House every year, and only 12p in every pound of this comes from government funding.

**We don't know what challenges tomorrow will bring, but what we do know is that with the help of Derian House we will make sure that every day of Amélie's life is full of love, laughter and sunshine.**



**"No matter what life throws at her, she refuses to be defeated."**

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At Derian House, the hydrotherapy pool is one of her favourite things. Because of her multi-sensory impairment, she loves the feel of water (a bath takes two hours because she won't get out!) Her tracheostomy means a public swimming pool isn't safe for her because of others splashing, but at Derian she has it all to herself. Knowing she can play safely with a physiotherapist on hand is priceless. Some of her happiest times have been spent in that pool. She also loves the park at Derian House and she has even been on an adventure residential trip to Northumberland with some of the other teenagers – looking at pictures of her beaming as she went on the zip wire made my heart burst with love and pride. Amélie doesn't tolerate going out to places where there are large crowds, she's autistic and has learning disabilities.

We were honoured to be one of the first families to use the brand-new cinema at the hospice, after Amélie helped cut the ribbon to officially declare it open in 2019.



# Amélie's Story

**WHEN our daughter Amélie blows out the candles on her 18th birthday cake next year, it will mark a milestone we never imagined she could reach.**

My name is Darren and I'd like to tell you about the care my family has received from Derian House Children's Hospice over the last 10 years to help Amélie live her life to the fullest.



This is Amélie

As you can imagine, with her bright eyes and cheeky grin, she melts hearts wherever she goes. But life hasn't been easy for our girl. Amélie was born with a rare genetic disorder called CHARGE syndrome. She can't hear or speak, and some days she can see better than others, due to her visual impairment. Amélie has a tracheostomy – an opening created at the front of her neck for a tube connected to her windpipe – to help her breathe. She is fed by a tube in her stomach, and she has a wobbly walk due to poor balance because of some missing parts in her inner ears.

But the way she compensates and utilises the senses she has got is incredible – she communicates through sign language and whizzes around computers.

**“She's very tactile and loves cuddles with her close family.”**

Amélie is the baby of our family and before her we had three healthy girls – Gabrielle, Olivia and Fleur.

We expected the fourth pregnancy to be the same and were planning a new life in France straight after she was born. But the day my wife Lesley gave birth, life changed for us all.

We knew straight away that something wasn't right. Amélie was put on life support after being born blue and limp. We noticed some unusual features, such as a missing lower earlobe. But nobody could give us any answers.

At three-weeks-old she was whisked for emergency open heart surgery. At four-months-old she had stomach surgery.

It wasn't until she was eight-months-old that a geneticist diagnosed CHARGE syndrome. The condition was so rare at the time that hardly any of the medical professionals had even heard of it.

But Amélie is a warrior. No matter what challenges life threw at her, our brave little girl refused to be defeated.

**“Her determination fueled ours and we vowed to do anything that could help her.”**



Our four girls, Gabrielle, Olivia, Fleur and Amélie

Amélie's big sisters dote on her and are always a huge help but looking after a child who needs 24-hour care is challenging and I ended up giving up work to be a full-time carer, while Lesley continued her career as a midwife.

We felt guilty when the girls were little because so much of our time was taken up living in hospital with Amélie. We felt like her sisters were constantly being passed onto grandparents and not given our full attention.

**“When Amélie was six years old, Derian House came into our lives and gave us the helping hand we so desperately needed.”**

Amélie began to go to Derian House for overnight respite stays, which gave us chance to rest and recharge.

A big challenge in caring for someone like Amélie is the lack of sleep. People with her condition do not need much sleep and she's hooked up to machines overnight so we're always up and down checking on her.

Some nights there can be three different alarms going off if one her wires or feeding tube gets a kink in it when she rolls over. You learn to survive on very little sleep.

There's also the little things most people take for granted, like being able to relax with a glass of wine in the evening. We can't do that together as one parent is always on caring duties. I recently pulled a muscle in my back and the doctor gave me strong painkillers, but I couldn't take them because they would make me too sleepy. Our whole lives revolve around Amélie.



Bags packed for a sleepover at Derian House