What would he be like if he were still with us?

12 YEARS AGO, LOUISE'S BROTHER ANDREW DIED OF NP-C. HE WAS ONLY NINE YEARS OLD.

Looking back

It feels so long ago since I last saw Andrew. As I was only six years old when he died, I have spent two-thirds of my life without him. Even though he was my older brother, in my memory he was small and fragile and I wanted to protect him as if he were the younger one.

"He will always stay the same in everyone's minds, as the young boy who didn't deserve to die"

Wondering - what if?

I often wonder what he would be like if he were still with us. He would have just had his 21st birthday, so he may have been graduating from university. I wonder about what he would have studied, which university he would have gone to, if he would be in a relationship and what his friends would be like. But the question I wonder about the most is if we would have got on. Many siblings argue a lot or develop an indifferent attitude towards one another.

"I like to think that if we had grown up together, we would have been close and still would be today"

A different life

If Andrew were still here and if he hadn't had Niemann-Pick disease, my life and that of my parents would have been very different. We would not have met so many people, been to the places we have been, experienced so many things and shared our story. Has it been worth it?

No. I would give up everything to bring him back, make him better, or even just spend one day with him. But since that opportunity will never arise…

"I guess all I can do, in my world of thick cloud engulfing the sun, is try to see that glowing silver lining"

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