

## *Goodbye, Ellie*



*She was born four years ago this month. Our beautiful daughter, a chubby bundle with soft, blonde hair and rosebud lips. For four years we watched her growing up, delighting in her progress. And now she is dead*

Even today, nearly two months on, I can't believe I am writing these words. My stomach tightens, I feel a pressure in my head and the tears begin to flow again. I am filled with numbness, horror, disbelief that this could ever happen to me. Yet here I am, telling you about the day my precious daughter died, the memory of which is etched into my soul.

We knew a few weeks after her birth that all was not well with Ellie. Our fears were soon confirmed by doctors. Although her condition was never diagnosed, she battled valiantly against cerebral palsy, visual impairment, epilepsy and chronic colic. But through her love and her pain, she taught us the essential truths of life. And now the intensity of our love for her, and the aching loss of her life, is almost unbearable.

That fateful day started slowly. Ellie, like the rest of the family, had been hit by flu. An agency nurse (provided at long last by the health authority, who had finally accepted that our family needed some help) had spent the night with her. I went in to Ellie at 7am after a difficult night, during which she had vomited and had difficulty breathing. I found her still asleep, and knowing that sleep is the best healer, I let her be.

Tears spring to my eyes again when I think of this. How could I have left her? Would she still be alive if I had moved into action sooner?

She wakes at about 8.45am, but doesn't move. She is clearly wiped out by this bug. I draw back the curtains; the sight of her fills me with horror. One side of her face is covered with dried vomit. It looks like a mask. It's an image I'll never forget.

The telephone goes, so I leave Ellie with my mum. It's a friend checking how I am. I tell her about Ellie's face – but why am I worrying about the state of her face when there are more urgent matters to deal with? I go back up, wash and dress Ellie and give her some water, which she manages to keep down.

She clearly had a severe chest infection which needed treatment, but first I decide to go to our GP. Why in God's name did I not go straight to A&E? But then, A&E always tell us that we should consult a doctor first. Somehow, even at this time of crisis, I seemed to be more concerned with doing the "right" thing for the NHS rather than doing the right thing for my daughter.

Ellie lies in my arms as we wait for the doctor, her lips a deep purple colour, drifting in and out of sleep. My lips and cheeks as usual are nuzzling the curls on top of her head.

On seeing Ellie, the doctor immediately calls an ambulance and ushers us into her treatment room to give Ellie oxygen. Still I don't worry. We have been through so many crises in her short life. Her lips become a bit pinker. Ellie is in good hands. These people will make her better.

Then the paramedics arrive and I enter a scene from Casualty.

As we leave the surgery, I wave goodbye to the receptionists. They all look so concerned, but I calmly wave goodbye to them. Sitting in the ambulance, the blue light flashing as we slice through the London traffic, I find myself thinking that I wished we could always get to Ellie's school this quickly. Her school was next to the hospital – but what a totally useless, stupid thing to think at such a time.

At the hospital, a team of registrars and nurses bustle around her trying to find a vein to administer fluid and antibiotics. Never an easy thing to do at the best of times. Still I am not concerned; I know they will make her better and give me back the Ellie I know, my girl with the cheeky smile. I stroke her hair when I can get close to her but sense I'm in the way and move to the corner of the cubicle. I still think there is no reason to call my husband Peter. He does nights with Ellie and was up late in case the nurse needed him.

As I pace the room, a nurse asks if there is anyone I can call. I say no, I'm fine, I'll call them later. Then they tell me they are going to assist Ellie with her breathing as it is using up so much of her energy. Assist Ellie with her breathing? This is unknown territory. Suddenly, I don't understand what is happening. I run outside and, needing some reassurance from someone who knows Ellie, I call Jackie, the nurse at Ellie's nursery. She says she'll come over as soon as she can.

I go back in. They have put a tube down her throat and a nurse is pumping a big green balloon. I stroke Ellie's hair and give her a kiss. It's the last kiss I ever give her.

I move out of the way again. The registrar bustles out with blood samples. On her way back in, she kneels down by my chair. "Ellie is very sick," she tells me, "we are trying to stabilise her but there is a possibility we might lose her." LOSE HER? What do you mean? Dear God, this can't be happening to me. Panic sweeps my body. Every molecule and atom in my body starts somersaulting. My eyes sting with tears but don't flow. I can't do this on my own; I can't handle this.

I run outside and call home. My mum answers and hands me on to Peter. I hear his voice and the first tears burst from my eyes in frightened childlike sobs. I need him. Desperately.

I go back in and the registrar, concerned that I am on my own, asks if I would like her to call Ellie's paediatrician. Yes please, I reply. I am now so scared. Out of my depth. Impotent. Helpless. Just like Ellie.

Martin, her paediatrician, arrives. "I don't understand," I blurt out. "She just has the flu. How could it have got this far?"

He puts his arms around me and I sob like a baby into his chest. Then Jackie and Tracey arrive from Ellie's nursery. They look worried. They too put their arms around me and we cry together. The nurse tells me that Ellie is stabilised and they need to prepare her to be transferred to another hospital where they have a paediatric intensive care unit. She is going to be OK after all, I tell myself. It was just a scare.

As they struggle to put another tube into her, I turn away, unable to watch any longer. But I feel a bit calmer. We will soon be back in an ambulance and everything will be all right again. Forgetting that I have

given up smoking a few days earlier, I go outside to buy a packet of cigarettes and smoke half of one before returning.

As I round the corner back into A&E, I see the nurse standing there, waiting for me. She rushes over: "I was trying to find you," she says. "Ellie's heart has stopped and they are trying to resuscitate her."

I can't reply. She leads me back into the room. My body goes weak; I start to shake and sob. Sheer panic. My eyes dart wildly around the room, as if searching for a solution, but I can't focus on anything. I bend over and sob into my knees. Arms are placed around me. "It'll be all right," Tracey says, but I can hear the panic in her voice. They sit me on a chair, but I can't watch any more. I just want to run away. Help me. Where's Peter? In between my heaving sobs, there are moments of terrible quietness. So this is how the story ends, I think, the four years of Ellie. But it can't. I'm not ready. She's too young. And nobody warned me.

The nurse kneels down by me. "They are continuing to try but it is not looking good," she says.

"Keep trying, keep trying. Don't give up on my daughter yet." Like so many other people have in the past, I think to myself. Minutes later the nurse comes over again. She repeats what she said before, clearly wanting me to tell her to stop trying, to let Ellie go. But I won't. "Please keep going until Peter gets here." I'm not strong enough for this. I can't make that final decision, and I can't face the final moment on my own. Then Peter arrives. He sees my face and immediately knows what is going on. He rushes past me and into the cubicle, straight to Ellie. I am so grateful for his strength. "Oh Ellie, oh Ellie," he cries.

I follow him and watch him bending over our beautiful daughter. "She's gone," he says to the nurses, who nod quietly. "Come to Daddy," he says as he scoops up the most precious little thing that ever happened to us. As he lifts her the nurses unplug her and remove all the tubes. This is it. She's gone.

Resuscitation stops at 12.12pm, Wednesday January 5th.

I watch Peter holding our daughter through my sobs, wanting to hold her too, but still not accepting it. Holding her dead body would mean I have accepted her death, and I haven't.

Minutes pass like this, with him rocking her, and then I suddenly have to cuddle her. Peter places her on my lap. Her soft warm body moulds into mine as I cry the cry of all mothers everywhere: Why didn't someone tell me she was going to die today?

We sit slumped on a bench in the corridor while they dress her. Finally they ask if we would like to see her. They usher us into a side room; she is lying on a bed with a teddy bear next to her. She just looks asleep – she can't possibly be dead. Yet she is so still.

I sit next to her, my face against her face, holding her warm, limp hands. I can't get close enough to her. I want to reabsorb her into my body, so we can start again. Forget this ever happened. But I don't pick her up. I don't want to disturb her peace. Thinking I might get another opportunity to cuddle her, I let her be.

They hand us a little booklet with her handprints and footprints and a lock of hair. Tears of horror, tears of disbelief as we kiss her goodbye. I see her cheek is damp with our tears.

We can't go home – home is where Ellie is. So we go to a bland hotel, a place to lose ourselves. The night passes in a haze. Periods of sobbing are now interspersed with periods of numbness, of deadness. Everything feels blank, devoid of meaning. Then the horror of what has happened hits again and the sobbing resumes.

I discover that crying has many forms, many tunes. And I play them all, thumping the bed in anger that somebody, something has taken my baby away. Without giving me a chance to ask why? It was all so quick. I didn't have time to protect myself. I can't imagine any pain worse than this.

Dear Ellie, you have not left a gap in my life. Loss, yes, desperation, yes, a myriad of confused questions, yes, but a gap? No – how could you have left a gap when you were my life. You had no siblings, no one to draw our focus away from you. My life has lost its meaning without you.

Oh Ellie. For four years I have lived for you, laughed for you, cried for you, fought for you and rejoiced for you. For four years I co-ordinated your care, battled for your rights, waded through the bureaucratic nightmare of having a disabled child. For four years, I was faced with a feeling from so many people that your life had no value, that perhaps your death would be a blessing. Oh Ellie, if only they knew what you had to offer, if only they'd listened. You never talked. But you found a way of connecting that went beyond words. Why couldn't other people see past your difficulties and see you as I saw you – a beautiful, spirited little girl with searching blue eyes and a cheeky smile. With so much to give.

At a meeting to fight for the nursery of our choice, the only nursery that could give you the complex care you needed, we showed a picture of you. We wanted the education "experts" to see the real you, our little girl. They pushed the photo away – God forbid that you become more than a number for them.

What a cruel irony is this, Ellie – when we needed the support so desperately during your life, we neither had the energy or the time to move the mountains of bureaucracy. Now we have time in abundance, but at the expense of your dear life.

Your death hasn't yet settled into me, hasn't been absorbed into my mind, my body. Will it ever? The loss of your life and your love still floods from me in vast rivers of anguish and despair. But your life was not in vain, Ellie. We will continue to fight as best we can to open the hearts of all those who can make a difference to the lives of children like you. We will do it for you, and for all the children whose cries go unheard, whose often contorted bodies go unseen, for their parents whose desperation renders them silent. In memory of you. Bless you, my angel, for the gift of your life and the legacy of your loving.

People tell me that when God closes one door, he opens another. Please help me, Ellie, please help me find that other door. I can't see the way through my tears.

Sarah Settelen

22 February 2000

*# The fee for this article will go to the Cheyne Day Centre to create a sensory garden for Ellie's friends. Any readers wishing to make a donation should send a cheque payable to The Cheyne Day Centre Amenity Fund to: The Cheyne Day Centre, Doughty House, Chelsea & Westminster Hospital, 369 Fulham Road, London SW10 9NH.*