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## Our life with – and without – our daughter



The hardest part of being a parent is seeing your child suffering and not being able to do anything about it

By Ruth Hartanto  
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Our year of firsts has come to an end. We have gotten through the first birthday and Christmas without her. On April 1 we got through the first anniversary of my daughter's passing.

Has it really been only a year? In some ways it feels so much longer. Our family's life changed significantly when she was born, and again when she died. I often think back to that night, driving back to the hospital at 3 a.m. after getting the call from the ICU staff, my mind and heart racing faster than I could physically get to her room.

There seemed to be a lot of people working on her and around her bed. I could see her eyes darting around and finally resting on me. "It's okay baby, Mommy's here."

Sydney was born with one of those rare syndromes that you never hear about until it affects someone you know - Coffin-Siris syndrome. As a result, she had a tracheotomy, a feeding tube and was attached to a ventilator for most of the day and could not be left alone.

The prognosis when Syd was born was not very good. We were told she would likely only be with us for a year. After three months in the neonatal intensive-care unit, we brought her home to love her for as long as we could.

It turned out that we had almost 13 years to love her, and during all that time Sydney decided she wasn't going to just lie in her bed and wither away. Development was slow, but she amazed us all. Sydney went to school, became good at using a touch-screen computer and walked short distances with a walker. She was non-verbal, but oh so vocal. Her guttural chuckles were infectious.

Always smiling and happy, Sydney was social and known as the school princess as she rode the hallways on her modified trike. Foam swords were her weapons of choice and the sixth-grade boys who played with her at recess dubbed her "Sword Master Syd."

We set up our house to accommodate Sydney's needs. Her bedroom was in our kitchen. Medical equipment and supplies were stored in the cupboards with the overflow in our dining room, hallway closet and basement. Although the beeping of the ventilator and feeding pump startled our dinner guests, we hardly noticed.

Our life was governed by nursing shifts. We had nurses overnight to watch her as we slept. We were in bed by 10:30 p.m. and back downstairs by 6:30 a.m. Weekends were tag games as my husband and I took turns staying home with Syd while the other took our two boys, now 12 and 9, to their activities or ran errands. I was in contact with our case manager or nursing agency or ordering supplies on a daily basis.

During those years, I often wondered what a normal life would be like, and here I am now, still wondering. In the movie *The Incredibles*, the superheroes had to give up their outfits and blend in with regular people. We too blended in after Sydney's death. We got rid of the porch elevator and the ramps we used to get her wheelchair in the van. We returned all the medical equipment or gave items to other families who could use them. We became a regular, plain old family of four.

The enormity of Sydney's medical issues and how they affected our life had pretty much set us apart from our family and friends. Her death changed everything again. We didn't just lose her - we also lost all those routines and all the people we dealt with regularly.

For months I cried every time I heard that distinctive chug of a wheelchair-accessible school bus driving down the street. When my husband and I were upstairs at the same time he would panic, thinking no one was downstairs with Sydney. I still hear beeping noises in the house, and it takes me a moment to realize that I was just imagining it.

The hardest part of being a parent is seeing your child suffering and not being able to do anything about it. Sydney's last days were the hardest. She had already been fighting something at home the previous week. We brought her to the hospital on a Sunday morning, assuming that it would be another routine stay. She would be admitted, given IV antibiotics for pneumonia and, in a couple of days, we would bring her back home.

By Tuesday, we realized that the medications were not working, that something else was going on. When we got to the ICU in the early hours of Wednesday morning, she looked so tired and was going downhill fast. The medical team suggested they could keep pumping her with meds, but it wasn't going to change anything. We could do nothing more.

Having to say goodbye to our daughter and cuddling in bed with her as she slipped away was the most unnatural, surreal experience. Yet, in another way it was normal and natural. We knew this time would come at some point; our life with her prepared us for it.

For almost 13 years, Sydney helped me find the strength I did not know I had, pushing me to do everything I could to make sure she had the best quality of life possible. I am still blown away by the amazing calmness I felt when my husband and I looked at each other, knowing that the time had come. There was no arguing, no second-guessing. We did everything according to Sydney, and this was going to be same.

*Ruth Hartanto lives in Ottawa.*