

The decision to accept disability: One family's perspective

Barbara Farlow BEngSci MBA

At 21 weeks' gestation, we were informed that our daughter, Annie, had a genetic condition associated with profound disabilities. Thus began the most difficult but, ultimately, most enriching journey of our lives.

We realized it was highly likely that Annie would require life-saving interventions in her infancy. From the outset, we wrestled with an agonizing, moral question: Would these interventions and the preservation of her life be in the best interests of our daughter and our family?

To make an informed decision, we began to research. We discovered children who were certainly very impaired, and we were afraid. However, as our knowledge increased, and we met more families with children deemed to be 'severely disabled', our fears were alleviated.

Shortly after Annie's diagnosis, I attended the funeral of a young man with severe cerebral palsy, who had never walked or talked. The midweek service was filled beyond capacity. After the service, I spoke to his teacher. Tears fell freely from her face as she told me that her student had 'changed her life'. How could that be?

Children with Annie's condition seldom live into their teens, yet we have observed that when their child dies, the families are absolutely devastated and by no means relieved to be free of their 'burdens'. These children were loved in the very same way as any child.

We did some very deep soul-searching about the purpose of life. We realized that the quality of our daughter's life was not ours to judge. We understood and accepted the many challenges and sacrifices Annie's life would entail. It would not be easy. Nothing worthy ever is.

Annie was born full-term and was mildly afflicted. Her only serious issues were hypoglycemia and an undiagnosed airway problem. Without a doubt, there were challenges. We spent the first six weeks in the hospital with Annie, and a family member was with her at all times – night and day.

Our children instinctively rose to the occasion to contribute. Our 12-year-old son took over lawn maintenance and prided himself in having the best grass on the street. Our teenage daughter left her summer job to help out. Even the youngest wanted to contribute, and drew endless pictures with 'I love you Annie' on them. We were so very proud to witness their automatic responses of protection, love and self-sacrifice for their sister.

We took nothing for granted, and we lived each day to the fullest. We laughed when Annie came home soaked from a sudden, unexpected downpour when she was out for a walk. One clear, hot night, when everyone was asleep, we

took Annie outside and looked at the stars together. Indeed, we viewed life differently once Annie was born. Her first smile was like magic.

Annie's life came to a sudden end within 24 h of arriving at the hospital at 80 days of age. She had been having episodic respiratory distress in the preceding days, and her paediatrician told us that it was best to take a conservative approach because the suspected tracheal condition might improve on its own.

It was with incredible and inconsolable sadness that we had come to discover that Annie's pulmonary health had deteriorated weeks earlier because her carbon dioxide levels were rising to critical levels.

Because we were unaware of the plan of treatment, and had no understanding that high levels of carbon dioxide could lead to rapid death, Annie's death was most difficult for us. She did not have the comfort we would have wished for her in her final days and hours. Annie's siblings rushed to the hospital only to discover that their sister had died just minutes earlier.

The coroner and his committee noted issues about our daughter's final admission. An effective 'do not resuscitate' order had been placed on her chart, yet this had not been discussed with us. There are no words to describe the pain we felt when we discovered that our rights as Annie's parents, to provide input into critical decision-making, had been overlooked.

The infant with predicted disabilities lives the most fragile of human lives. The fate of our child rested in the hands of the physicians and health care providers. Unilateral treatment decisions and the absence of our input into or awareness of these decisions caused a double tragedy. We were denied both a chance to prolong Annie's life and a plan for her to die a dignified and peaceful death with her loving family by her side.

Some would say that helping a child like Annie live longer by offering more aggressive medical interventions would be unfair and burdensome to the child and family, and an irresponsible use of limited societal resources. We believe that parental involvement and consent in treatment decisions are acutely important issues. When they are overlooked systemically and without cause, there is a necessity to reflect on the implications.

We have learned that accepting and making sacrifices for Annie was deeply personal and purposeful. It was a privilege. It was about reaching beyond the definition of 'perfect' provided by consumer culture endeavours and health care policies. In short, it was an act of love.

Member of Patients for Patient Safety Canada, appointed member of the Communication and Information Advisory Committee of the Canadian Patient

Safety Institute and a World Alliance for Patient Safety Champion

Correspondence: E-mail b_farlow@hotmail.com

Accepted for publication April 9, 2008