

Barbara Farlow, "Misgivings," *Hastings Center Report* 39, no. 5 (2009): 19-21.
20 HASTINGS CENTER REPORT September-October 2009

Misgivings BY BARBARA FARLOW

Our daughter Annie was diagnosed with Trisomy 13 before she was born. Most infants born with the condition die shortly after birth, but some live for many years. We exhaustively researched medical publications and parents' stories about children with this condition. After much contemplation, we decided to carry to term, and to consider medical treatment to prolong Annie's life. This was a decision that we would likely not have comprehended before our journey began.

We knew that our decision was not a common one and that the doctors might not understand or agree with it. For this reason, we met with doctors from the cardiology, genetics, and bioethics departments at the children's hospital before Annie's birth to inquire if she would be eligible for surgery if it was necessary. We were assured that surgery would not be denied based on a genetic diagnosis alone. The policy that outlined the determination of levels of treatment and the process for resolving ethical dilemmas between families and doctors was described in detail to us. Later, after we'd obtained the hospital's records, we read what the bioethicist had written about us at that meeting: "Calm, articulate, logical, framed in *best interest* logic. Want to give baby every opportunity for quality of life . . . don't want life of suffering."

Remarkably, Annie was born full term with a good weight, excellent Apgar scores, and normal muscle tone, strength, and reflexes. Unlike most infants with the condition, she could see and hear, and she did not have the common brain and heart defects. We had reason to hope. No discussion related to palliative care ever arose during that time. We articulated our desire to give Annie the same chances as a child without disabilities. There were silent nods of assent.

We were new to the complexities of caring for a child like Annie and frightened of the uncertainties. We were on a difficult journey that would inevitably lead to Annie's death. We depended on our primary care doctor, Dr. David, as one would depend on a life preserver in turbulent waters. Over the course of Annie's brief life, we developed an excellent relationship with him. After six weeks on the ward—mostly for treatment of Annie's hypoglycemia—we were elated to be discharged home. We were incredibly grateful for the wonderful medical care Annie had received.

Weeks later, Annie began to have episodic respiratory distress. At a clinic visit, Dr. David told us that a conservative approach was best and that the problem might resolve itself. No tests were ordered. The distress worsened, and the next day we went to our regional hospital. The doctor immediately sent us to the children's hospital by ambulance. When we arrived, we were relieved to see Dr. David in the emergency room waiting for us. After he reviewed the blood work and x-ray, he told us that the team thought Annie had pneumonia. This seemed like good news. We believed that children can recover from pneumonia.

Hours later, Annie suffered a respiratory crash on the ward. Dr. David took an arterial blood sample and left. We stood there, distressed and alone with a therapist who manually ventilated Annie with a bag mask for over an hour before transferring her to the pediatric intensive care unit.

Sixteen hours later, in the PICU, Annie's oxygen saturation numbers suddenly plummeted, and the therapist again started to manually ventilate her. Within minutes, Dr. David and the intensivist were there. The intensivist asked whether he should intubate and said that the problem was *not* pneumonia. He described a difficult surgery that Annie would likely not survive. Dr. David stood beside me. I put my hand on his shoulder and asked, "What do you think?" He knew us better

than anyone, and we trusted him. We needed him to guide us to make the most important decision of our lives. He indicated that not intubating Annie was the right choice. He stayed with us until Annie died a short time later and then returned to spend time with our family in the bereavement room.

Although I felt guilty, ashamed, and ungrateful to be so suspicious, I ordered Annie's medical records to look at the events of her last hours. I was shocked by what we found.

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Within days, I had a nagging sense that the events that had transpired did not seem logical. In the emergency room, Dr. David, the emergency doctor, and a fellow from the intensive care unit had all looked at Annie's x-ray before a diagnosis of pneumonia had been made. Surely this was an accurate diagnosis if it had been made by three doctors. Yet just twenty-four hours later, we were told in the PICU that the cause of her acute respiratory distress was *not* pneumonia. Although I felt guilty, ashamed, and ungrateful to be so suspicious, I ordered Annie's medical records and asked a friend who was a nurse practitioner to take a quick look at the events of her final twenty-four hours. I was shocked by what we found. The intensivist had placed an order not to resuscitate Annie hours before we had consented to this. This discovery was like the first domino in a long line of questionable events that made us realize our last conversation with Dr. David was a charade.

We spent months researching and consulting with specialists as we struggled to obtain more information and insight. As the bond of trust we had with Dr. David began to tear, we held tight to its shreds, always hoping for an explanation because what we were discovering could not possibly be true.

It took over two years, an internal hospital review, an investigation by the coroner and his pediatric committee, and a private medical review for the facts to be exposed, understood, and accepted. We learned that Annie's carbon dioxide levels became dangerously high on the fifth day of her life. There were multiple indications that her condition was worsening. A senior pulmonologist had suspected tracheal stenosis and suggested simple tests to rule out other, less severe conditions. These had been ordered and then inexplicably cancelled. We knew nothing about any of it.

When Annie arrived at the emergency room twenty-four hours before her death, she had no indications of pneumonia. The records also revealed that Dr. David had not called the PICU for over an hour after Annie had "crashed" on the ward. As a result, Annie was left to suffer what some call a "slow code blue," in which the medical team does not undertake resuscitation steps with the usual rapidity. Several PICU records were also inexplicably missing, but the final assessment, one hour before her death, showed that Annie had good blood pressure and a 97 percent oxygen saturation rate, indicating that with the right care, she may have had a good chance of surviving her crash.

The coroner's report declared that the events of Annie's final admission "do not represent appropriate forms of care," and added, "it was by no means certain that she would have to undergo prolonged burdensome interventions such as prolonged ventilation or distressful surgery." To this day, it is unclear to us whether our daughter's death was preventable or inevitable. In either case, Annie had suffered terribly and unnecessarily as she slowly

asphyxiated to death. The lack of transparency in the treatment plan ensured that she received neither appropriate lifesaving care nor effective palliation.

The hospital provided a written apology, informing us that “sometimes when we care for children such as Annie who have very complex care needs . . . communication does not occur in as clear and consistent fashion as we would wish. For that, we are very sorry.”

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There are no words to describe the impact of these revelations on my family. It went beyond tears and anger; it was gut-wrenching and physical. We eventually came to a place in our hearts where we were prepared to meet with the doctors involved with the hope of reaching understanding, closure, and peace. Despite an offer we made to “sign anything” in case they feared repercussions from the coroner’s declaration that the care Annie received was not appropriate, the doctors refused to meet with us. The last remaining thread of our trust—now in the form of hope for apology and forgiveness—was gone.

The pain and anguish of all that occurred propelled me to become an ethics and patient centered care advocate. I found the courage to tell Annie’s story at regional, national, and international conferences. At one of these conferences, a presentation was given on priority-setting strategies. The presenter was a pediatrician who developed pediatric priority-setting strategies to reduce surgical wait times at children’s hospitals in our public health care system. She explained that “values” were one of many factors influencing the strategies. We spoke at length afterwards. She told me that the values used to develop strategies were those of the majority of the public. She seemed flummoxed by my question, “But what about human rights and the value of autonomy?” I told her that all rationing strategies must be transparent. It is unfair to doctors and patients alike to covertly implement strategies that withhold care from children on the basis of unilateral quality-of-life determination when there is no justification of medical futility. I am usually very guarded with my emotions, but this conversation caught me off-guard. The pediatrician watched, confused, as tears dripped from my face.

Finally, we had a chance to better understand the events that had occurred with Annie’s medical care, including the failure to diagnose the cause of her ongoing, serious respiratory condition and the tragic “slow code blue” on her final day. The situation was likely not as simple as making best-interest, informed medical decisions for Annie. There were other children and limited resources to consider, as well as value judgments and choices for her doctors to make.

In the days following Annie’s death, her big sister had made a beautiful scrapbook of her life. One page is entitled “Very Special People,” and there, in the center, is a picture of Dr. David holding Annie. We took the photograph in the hospital bereavement room when we suddenly realized that we did not have a picture of Annie with her doctor. His countenance is difficult to read but suggests to us an element of discomfort. We may never know with certainty why he withheld information, provided misinformation, and took Annie’s chance at life away, leaving her to suffer and die without a palliative care plan. However, we have chosen to keep the picture in the book. We hope that perhaps in some ways, Dr. David was a victim of the hospital culture and the medical system. We want to believe that his expression in the picture reflects apology and regret.