

# TRANSCRIPTION

**cpsi Canadian Patient Safety Institute**  
**iscp Institut canadien pour la sécurité des patients**  
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**Patients for Patient Safety Canada**

**[0:00:08]** The story begins with a prenatal diagnosis from an ultrasound that my daughter, who at that point, was about 22 weeks gestation, had a genetic condition that's associated with some very grim statistics. Many of the babies die before they're born. Many of them die shortly after they're born, during labor. But about 10% of them live beyond a year. They live for many years, generally not until they're adults.

**[0:00:38]** The children who survive are disabled, but they're very happy and their families are happy. So based on the information that we obtained, we had to think long and hard. Obviously, very significant decisions. But we decided that if our daughter had a chance to survive and if she could live comfortably, we didn't want her to live on machines. We didn't want her to live a life that she would be hospitalized every second week. But if she could be happy and comfortable, that we wanted to support her with that life. Statistically, the likelihood was that our daughter would die very young. and we needed to know that we had made the right decisions, that we had no regrets. And so that's where we were headed.

**[0:01:19]** You can imagine how we felt when she was born seven pounds, full term. Apgar scores of eight and nine out of ten, which is very good numbers. Really, it was quite rare to have the absence of these two major conditions that are so significant in terms of ability to live to longevity in life.

**[0:01:40]** So Annie came home at six weeks and it was quite a celebration, especially given the statistics that we had faced throughout the pregnancy. The children decorated the driveway with chalk as signs like "Annie kicks butt" and "You rule" and "You were small and now you're big." It was a really special day to come home.

**[0:01:57]** Annie smiled for the first time when I played peekaboo with her when she was about 75 days of age. And fortunately, my husband was there and saw her one and only smile. So that was very special to us.

**[0:02:11]** Well, when Annie was about 77 days old, she developed episodic respiratory distress and her face turned and stayed red. The doctor told us that she might have something called tracheal Malaysia, which means a floppy trachea, and that these kinds of conditions can resolve themselves and that they always take a conservative approach about them.

**[0:02:36]** Then we, two days later, went to see the primary physician at the children's hospital, and he said the same things. When Annie was 79 days of age, the respiratory distress, she had an episode that was much worse and didn't resolve itself. And we went to the local hospital and they transferred us by ambulance to the children's hospital. He told us that Annie's trachea, which had been the concern, was fine and that she had pneumonia.

**[0:03:02]** So the intensive care doctor came. And he asked us, if she should stop breathing, whether he should resuscitate her, whether he should put her on life support. And I told him yes, because we had been told she had pneumonia, and children get better from pneumonia. And he asked the question again. "So I need to know whether to resuscitate." And I said we needed to make an informed decision. We needed to know what the cause of our daughter's respiratory distress was and whether we could or should fix it.

**[0:03:35]** Through the night, the intensive care doctor told me that she needed surgery for a trachea that's too small. It's called tracheoplasty. And we knew that our daughter's health was fragile and that the mortality risk for this surgery for children who were otherwise normal and healthy was very, very high, especially at this age of 80 days. Clearly, this was not something that looked like a good idea for our daughter.

**[0:04:04]** In the morning, my husband and I were taking turns showering and getting dressed. And when I was gone from the room, I returned and found there was chaos, that the numbers had suddenly started to plummet. My husband later told me that he was sitting alone and saw the numbers plummeting, but the alarms had been silenced, and he just noticed silently the numbers were dropping. And the nurse was gone, the 1 to 1 nurse. And he called for help from the other nurses, but they didn't come. And the primary physician was standing beside me. And I actually put my hand on his shoulder and I said, "What do you think?" He was a lifebuoy. He was our most important partner. And he said, "It looks like it's not pneumonia." So we agreed not to resuscitate. And Annie passed away, I guess about 45 minutes later.

**[0:04:59]** When I reflected back, that in the emergency room, we had been told that Annie had pneumonia and that her trachea was fine, and less than 24 hours later, she didn't have pneumonia and she needed this surgery that was not in her best interest, it just seemed confusing to me how things could turn around so quickly, how a diagnosis of pneumonia could be made, and then she didn't have pneumonia. I don't have a medical background, but that did seem confusing to me.

**[0:05:29]** And so it just continued to play on my mind. My husband agreed that, well, why don't we get the medical records? And the goal really was to seek assurance, to understand how this happened so that we could move on. The day that I was ready to put them away, I met a woman who had worked in pediatric intensive care for many years, and I shared our experience with her and told her I was confused. So it was she that

showed me that a “Do not resuscitate order” said “not for intubation” had been placed in the records actually several hours before we had provided consent. And that was just so shocking to me. Even though I believed at that time we had made the right decision, the fact that somebody had placed that order was just a terrible, terrible violation to me.

**[0:06:18]** It was really like the first domino to discover that order had been placed, because then we started to look for more things. And what we found was that all of the final records were missing or absent, never created.

**[0:06:35]** In time, the Coroner's Pediatric Death Review Committee reviewed Annie's death. And they concluded that the care provided was not appropriate. But more significantly, they also declared that the surgery that we had been told about was by no means certain. And so then we were left wondering if our daughter possibly could have still been alive.

**[0:06:59]** We really struggled to understand and to forgive the providers. Of course, initially we're thinking that the doctors did the wrong thing, but then when we dug further, we saw that there was a system that they were acting in, perhaps related to shortage of beds, perhaps related to culture of the hospital and the kinds of children that maybe should be treated. And then even looking beyond that, beyond the hospital, what we found was that there was a general standard of care for children like my daughter.

**[0:07:27]** Myself and Dr. John Vey [ph] and also Dr. Wilfond [ph] from Seattle Children's Hospital, together, we all agreed that we had to do something to provide a voice for children like my daughter and other children, really, that the standard of care for these children needed to change, that the family experience, the parental experience needed to be included in the literature. And it wasn't.

**[0:07:56]** We had the largest sample size that anybody's ever had on this cohort of parents. And it was really quite incredible. And our first paper was published last summer in the most well-read pediatric journal called *Pediatrics*. And the Journal actually issued a press release. And we had over 60 articles in five languages around the world. And the parents were so excited because they've been struggling with doctors. The challenge of raising a child that can be medically fragile and have disabilities was nothing compared to the challenge of finding good doctors, doctors who understood. And what we found in the paper was that 97% of the people described their children as happy children and that they enriched their lives and they were beneficial to the siblings. And parents felt that siblings would grow to be better adults as a result of the influence of their children.

**[0:08:47]** So another way it's changed my life, the experience with my daughter, has been through my work in Patient Safety. I've been a member now for over six years of Patients for Patient Safety Canada. I'm also the honorary board member, patient perspective board member for the International Society for Quality and Health Care. Annie really brought our family together because we all had to give of ourselves completely. I felt that we were

acting in her best interest. To this day, I do. And so it was, for me, a very, very significant need to redeem myself, that we did do the right thing for Annie. And that way, I guess, to forgive ourselves for the suffering that she endured that she shouldn't have, that we – wasn't our fault, that we did the right thing.

**[0:09:37]** It's had a very big impact on our lives, my life, my husband's life, our family's life. I think the main messages that I would like to share really relate to not only children with disabilities, but really any vulnerable patient where the evidence-based statistics suggest that they will die soon, to try to see that through the parents' or the family's eyes or the patient, if they're able, and to understand what they understand and think about the condition, what their expectations are, and to respond to those expectations appropriately.

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