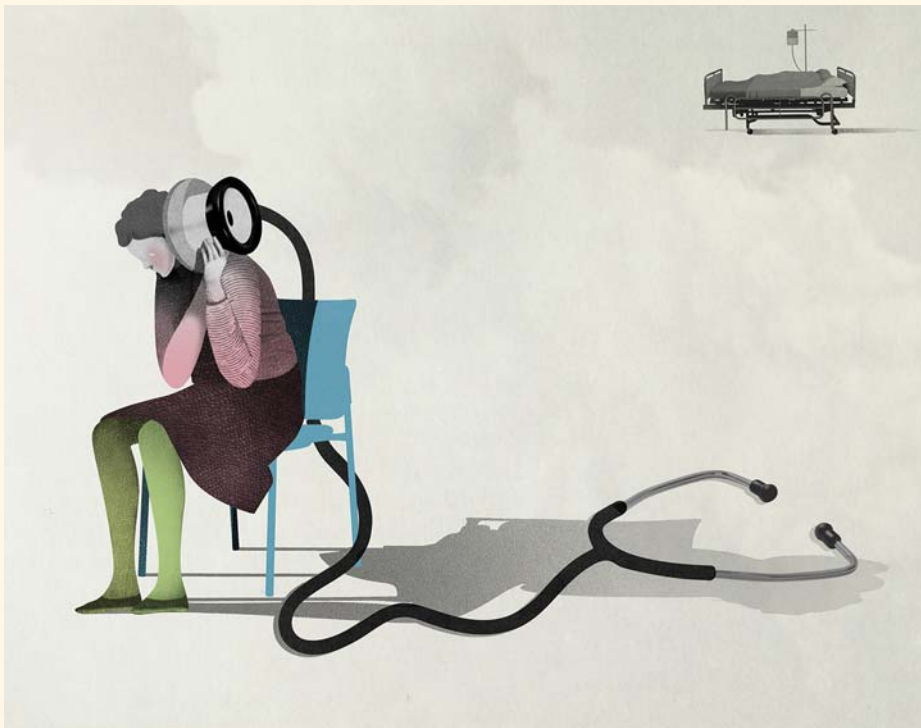


# NARRATIVE MATTERS



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## Seeking Answers, Hearing Silence

*A young girl dies ten days after receiving a leukemia diagnosis. The silence her family is met with afterward causes additional harm.*

BY CAROLE HEMMELGARN

**S**ilence is like white space on a sheet of paper: a void. After patient harm—in our case, after a death—that void becomes a secondary trauma. And it's a norm that still prevails in medicine today.

Her name is Alyssa. She was an energetic, lighthearted, quirky nine-year-old girl. She liked soccer, making puff-ball art creations, reading, writing stories, strumming her guitar, and playing animal games with her six-year-old brother. She couldn't have known that the simple joys of hanging out with friends, laughing with her brother, and sharing dinner

with her family would disappear so quickly. One day she was skiing a Blue-level, groomed run in the sunny Rocky Mountains, and the next she was lying in a bed in the bone marrow transplant unit, diagnosed with acute lymphoblastic leukemia.

The signs for leukemia are not always overt. For Alyssa they materialized in the form of a cold sore that wouldn't heal for two weeks, swollen glands in her neck, a bloody nose that appeared out of nowhere on our family ski trip, and lethargy so great that playing with her cousins and brother became a demanding task.

On the Monday morning after the ski

trip, February 26, we went to see her pediatrician. He conducted a physical, took her history, and drew blood to run some tests. I thought for sure she had mononucleosis. I should have known it was more serious when the pediatrician was adamant about having every phone number where he could reach me. I was not prepared for the news I received when the phone rang later that afternoon. That was the moment our world collapsed.

In many ways it would be easier to say leukemia took her life, but unfortunately that is not the case. On Thursday, March 8, ten short days after her leukemia diagnosis, Alyssa's health took a dramatic turn, and she died. Clearly, something went wrong in her care. However, her story is not about the hard science and clinical aspects of medicine. It is about the qualitative side, the conversations that don't always transpire between patients, families, caregivers, and health care organizations after patient harm occurs.

### The Last Adventure

For nine days Alyssa's care proceeded as expected. She was enrolled in a study protocol for acute lymphoblastic leukemia that was looking at two different treatment options, and we were excited when she was placed in the arm our hematologist thought was the most effective. A spinal tap was performed to directly inject chemotherapy into her body, and a port was placed in her chest where she would receive future treatments. The hardest part was not being able to leave the hospital room with her until the culture came back negative for her cold sore, indicating that she did not have a herpes simplex virus.

Little did I know that when we were finally cleared to depart the room and explore the hospital, it would be the final adventure Alyssa ever took. We rolled Alyssa down to the lobby in a wheelchair to visit the gift shop—she liked touching the soft stuffed animals. We listened to the sounds of the ball machine echoing in the front lobby as balls whirled round

and round, captivating onlookers. We visited other floors of the hospital, each with different artwork hanging on the walls—from photographs of animals to children’s drawings. It would be the last time I saw mischief in Alyssa’s eyes and the smile that revealed her tiny dimples. It would be the last time I heard the innocent laughter of my nine-year-old daughter. The last time I heard her whisper the words “I love you.”

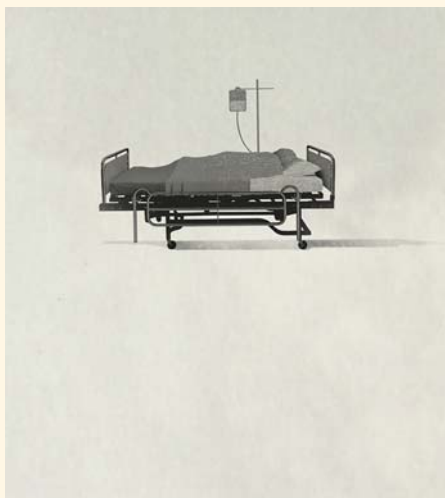
I remember the final hours of her life so vividly. We made a swift transition from loving parents to frozen spectators. I stood like a statue next to my husband in the pediatric intensive care unit (PICU) watching the medical team put IV lines into every possible part on her body from head to toe and pumping her with fluids and antibiotics. When this was not successful, she was prepped for surgery, so they could open up her belly and salvage what they could of her intestines. The hallway was cold and silent as we walked beside her still body and looked into her vacant eyes on our way to the operating room. We stopped only briefly, for the priest to give her last rites.

No parent should have to make the decision to end their child’s life. I lay down next to my daughter on a cold metal gurney in the PICU. The IV lines that had once adorned her body were gone. Her stomach was packed with gauze and other material and not completely sewn up, so I draped my arm across her chest and held her close, until she no longer swallowed and breath ceased to pass her lips.

## What Happened?

We left the hospital with her meager belongings and her favorite stuffed companion, a white bear named Valentine—about four inches long and holding a red heart in both his hands—that her grandparents had given her. As we drove through the sunny city streets on our way home to the suburbs, Valentine rested in my lap. I gazed out the window at the people walking down the sidewalk as though it were a normal day, while the voice inside my head was screaming, “Don’t you know my daughter has died, and our world has stopped?”

For days, I kept thinking the phone would ring and someone would tell me



what had happened. Instead, we received a condolence card from the hospital’s bereavement office saying how sorry they were for our loss. “How can they be sorry when we don’t even know what happened to our daughter?” I thought. Then the bills started pouring in, while the phone remained silent. Over the weeks, months, and years after Alyssa’s death, I reached out to different people in the organization, trying to piece things together and get answers. There was a gaping hole surrounding the last sixteen hours of her life. Things were not discussed. Unfortunately, that hole remains today.

When errors and harm occur, there is typically not a single cause. Over time, we pieced together some additional details: Alyssa had contracted *Clostridium difficile*, a hospital-acquired infection. After she died, her lab results were sent to the Centers for Disease Control and Prevention. (There was concern about a virulent strain on the oncology floor.) Two lab tests had been ordered the evening her health started declining, a D-dimer test and a fibrinogen test (to rule out a blood clot or bleeding disorder), and when the results returned they were posted as critical values. In other words, they should have been acted upon with urgency, but they were not. Alyssa became septic, and based on the information in her medical record, she became a classic case of “failure to rescue.”

No one in the organization where Alyssa died came to work with the intent of harming her. She was a small piece in a complex health care system, where holes aligned and mistakes slipped

through. While it is difficult to understand how this happens, the trauma becomes even more egregious when silence is all you receive from the organization in the aftermath.

It took us three years, seven months, and twenty-eight days to have the first honest conversation with the hospital. I counted every one of those days: Each morning when I awoke, I walked into Alyssa’s unchanged bedroom and apologized to her for not being a good mom and keeping her safe.

I carried an immense burden of guilt. It was difficult to function in a world of “what ifs,” constantly questioning the decisions I did or did not make. The longer we struggle for answers, the more grief becomes like our twin, and loneliness and isolation our constant companions. Being met with a wall of silence when you need to know the truth is cruel and inhumane. When patients and families are not told exactly what happened to them or their loved one, they are harmed again. It becomes a second tragedy and a second trauma.

In our case, there were many reasons why it took so long to get answers. There were barriers erected by risk management, incomplete medical records, a leadership change at the hospital, fear on the part of Alyssa’s health care providers, and the lack of a standardized process for how to handle severe medical harm or loss of life.

## Times Are Changing

In the years since Alyssa died, I have seen positive changes. More organizations are starting to implement communication-and-resolution programs, which encourage institutions to reach out to patients and families after harmful events, seek resolutions such as an apology or reimbursement, and learn from the event so the same thing doesn’t happen again. Hospitals also see the emotional and psychological impact of the burdens placed on caregivers and are creating programs such as Care for the Caregiver to assist with their needs. But there is still more work to be done.

There are no set templates or guidebooks to follow on how to interact with patients and families after tragic events. But the most important thing is to reach out, start a conversation, and listen with

## Policy Checklist

**The issue:** After patient harm or medical error occurs, patients and families want to understand what happened. Instead, they are often met with silence from the health care organization and providers who treated them. Open dialogue with patients and families after harm occurs would ensure that the secondary harm of silence is not inflicted.

### Related reading:

Allen M, Pierce O, Zamora A. The voices of patient harm. New York (NY): ProPublica, <https://www.propublica.org/article/patient-safety-voices-questionnaire-results>

Hemmelgarn C. Silence a commentary. Rockville (MD): Agency for Healthcare Research and Quality; 2017 Aug. <http://www.ahrq.gov/professionals/quality-patient-safety/patient-safety-resources/resources/liability/advances-in-patient-safety-medical-liability/silence.html>

McDonald TB, Helmchen LA, Smith KM, Centomani N, Gunderson A, Mayer D, et al. Responding to patient safety incidents: the “seven pillars.” *Qual Saf Health Care*. 2010;19(6):e11.

Mello MM, Boothman RC, McDonald T, Driver J, Lembitz A, Bouwmeester D, et al. Communication-and-resolution programs: the challenges and lessons learned from six early adopters. *Health Aff (Millwood)*. 2014;33(1):20–9.

Rowe M. The rest is silence. *Health Aff (Millwood)*. 2002;21(4):232–6.

one’s eyes and ears wide open and mouth closed. So often patients and families just want to be heard, share their stories, and try to regain some of the power they feel they have lost. Patients and families will typically tell you what they need if you just ask and are willing to listen.

It can take days, weeks, months, or years for patients and families to gather the emotional and physical strength to conduct these conversations. Health systems and providers need to meet patients and families on their terms and when they have the capacity, not just when it works for the organization or care team.

When patients and families *are* willing to meet, know that they are providing health systems a gift: the opportunity to learn what they experienced, saw, and believe happened with their care or a loved one’s care. They are present twenty-four hours a day, while the health care providers are visitors to their world for brief periods of time. Often, they will extend their gift and ask to work with

the organization to create a solution, so that what happened to them will not happen to someone else.

Starting the dialogue is the first important step and can help soften the aftermath of tragic medical harm, elements of which patients and families will experience throughout their lives. We are just starting to recognize the downstream impact of harm on the emotional, physical, and psychological well-being of parents, children, siblings, spouses, and partners. Some struggle with the financial burdens that can result from medical bills, loss of jobs, and failed marriages; others can bear the pain no longer and end their lives. For patient advocates like me, nothing haunts us more than the conversations we never get a chance to hear. It’s a kind of silence that screams in our ears.

## Disrupting The Silence

At the Diagnostic Error in Medicine 10th International Conference in 2017, Donald Berwick, president emeritus of

the Institute for Healthcare Improvement and former administrator of the Centers for Medicare and Medicaid Services, discussed actions that must persist if we are to advance the patient safety environment. Among them, he said, patients must continue to share their stories. His words were like a dagger to my heart: If stories were still being told, it meant that harm was still occurring.

Those of us who start out in the patient safety world—loved ones who have witnessed harm or loss—usually do so by sharing our stories. These stories are the voices we need to hear to keep our loved one’s spirit alive and help us face another day. Our stories create a force so powerful that we are willing to relive the pain repeatedly as we share them again and again. We do this because we don’t want what happened to our loved ones to happen to anyone else. It has been eleven years—in some ways long, in some ways short—since Alyssa died. You can understand how time freezes and moves forward simultaneously only when you have lost a child. I continue to share her story and still cry every time I do. What I fear most is the day the tears no longer roll down my cheeks. I worry that it will mean I have lost my connection to her, and her story.

I would do anything to have Alyssa back, but I know that wish will never come true. The gift she gave, and continues to give, is her story. Her story is data with a soul. My role now is to translate it into tangible action and mitigate the potential for others to experience similar harm.

A Chinese proverb states, “When the winds of change blow, some people build walls, others build windmills.” Our stories are windmills, and they generate power. They disrupt the silence. ■

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