



# A Forbidden Island

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AS I APPROACHED the pulpit, my body was telling me I was not ready. I felt my heart racing; my mouth was dry, my palms damp. I had long considered myself an extrovert, in my element with an audience to address, familiar with the clarity and the sense of purpose that accompanies giving a talk or presentation. Yet on this day, my physical reactions signified an unfamiliar feeling: anxiety, even fear.

When I received the invitation many months earlier to present a physician's perspective at The Children's Hospital of San Antonio's annual remembrance service, I had felt honored. I knew that the pews would be populated by parents, grandparents, and siblings who had experienced the loss of a child under our care.

As the event drew near, I felt less sure of my footing. I expected that to be an effective speaker, I needed to identify a point of commonality with my audience, to establish shared purpose at that time and place. As a pediatric hematologist/oncologist, I have done my best to help families navigate mortal situations and have appropriate hope during end-of-life care. However, I have not experienced the death of my own child. The families I would be addressing had joined an exclusive club, the initiation to which I cannot begin to imagine. Instead, I was to stand before these families as an imposter, a representative of the medical science that had failed to save their children.

I teach trainees about the importance of empathy when communicating with families. And yet, I wonder if true empathy—the ability to understand and share another's feelings—is even achievable sometimes.

While planning my speech, I reviewed a video recorded by a parent volunteer many years ago who had helped design a training session for pediatricians in breaking bad news. In it she describes her feelings on learning of her son's illness as being “plucked onto a forbidden island.”

I use that video to teach students, residents, fellows, and faculty colleagues. Following this mother's poignant observation, I show a photograph of a family of cormorants standing on an isolated rock off the shore of Cape Cod. I reflect that watching a family emotionally stranded on that island, my natural impulse as a physician is to

reach out, gather them up, and bring them back to the mainland shore with me right away.

However, perhaps a better expression of empathy would be to join them on that island, to say, “I cannot know what you are going through, but I am trying to understand.” Before we delve into a plan, before the medicine starts, before the labs, scans, surgeries, medications, tubes, and wires, we can try to be present, we can listen.

This is how I have attempted to practice empathy. And yet, it seemed insufficient as I turned to speak to the families that I felt we had failed.

Standing at that pulpit, facing the bereaved families while distracted by my own anxiety, I decided to own the truth. “Most of you in this sanctuary have lost a son, daughter, sister, or brother. I cannot know what you have felt. In gathering here today, we celebrate the lives of children who have touched us by sharing stories in remembrance of life. I would like to share a story of a little boy I met as I was learning to be an oncologist.”

I recounted the story of “Aaron,” a 2-year-old boy who seemed to have a toddlersque injury. He had bumped his head on a car door and developed a “goose egg” over his right eye. Yet the contusion continued to grow over several weeks. His pediatrician sent him to us when another lump appeared on his right leg, without a prior injury.

When we imaged Aaron, he demonstrated not just 2, but dozens of tumors throughout his body, including in his eyes, brain, lungs, belly, arms, and legs. He was diagnosed with undifferentiated sarcoma by biopsy. Over the course of 3 days in the hospital, Aaron's tumors grew visibly larger every few hours. He developed pain, vomiting, and vision problems as the tumors in his head continued to progress rapidly.

Aaron was the first patient I'd seen in my career who had no route to a cure of his cancer.

Meeting with Aaron's family, I told them that we could offer chemotherapy or radiation with a goal of delaying the progression of the tumors and palliating their symptoms. I told them cure was unlikely, and that treatment would prolong his hospitalization. Instead, they enrolled Aaron in a hospice program with a goal of going home as soon as possible. Our nursing staff trained Aaron's parents

in the home administration of medications to control pain and nausea.

Aaron's pain rapidly deprived him of the ability to walk. We gave him a backpack-equipped IV pump for morphine, allowing him to go on short outings. His father made a list of experiences he wanted to share with his son. They went to a movie theatre and ate popcorn, went out for ice cream, and went fishing and hiking. Aaron lost his vision and slept much of the time, carried nearly everywhere by his father. Our child life and social work teams facilitated an urgent Make-A-Wish, and a new swing set was installed in the family's backyard a week after hospital discharge. Aaron spent hours every day on that swing.

For nearly 3 weeks, Aaron lived. And then he was gone.

Each year since Aaron's passing, his social worker e-mails me on his birthday to give me an update about the family. His older sister remembers him and is beginning to understand what happened to him. He has 2 younger

brothers now, who I imagine are growing up to learn about how warm, energetic, and spirited Aaron was. I hope that Aaron's story will continue through each of us who knew him.

I told the families Aaron's story. I told them about the nurses, nurse practitioners, social workers, child life specialists, pharmacists, physicians, and many others who form teams to help families on a forbidden island become ready to return to the mainland shore. I thanked them for entrusting us with the responsibility and privilege of caring for their children. I reflected on the importance of hope. Although we could not expect a cure for Aaron, his family still had hope: hope for each day without pain and nausea, hope for him to feel loved and comforted, hope for him to live without fear, hope for him to have ice cream with his dad and to ride the swing in the backyard. In that moment, I felt we were the cormorants together on the island, wings furled as we looked out to sea.