Desperation. Exhaustion. Fear.

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ABSTRACT

The mother of a medically complex child explains how she lost trust in the child's medical team when the lead physician did not present all of the options for the child's care. Over a period of years, the medical team regained the parents' trust with their compassion, honesty, and lack of bias.

These are a few of the emotions that thickened the air when my child was in the depths of struggling for his life in the hospital. These emotions were not new to us as parents of a medically complex child. We had been there often. Our son became a part of our family right after his first birthday. We knew when we committed ourselves to him that his life was not going to be an easy one. He was born healthy, or so it appeared, until a fever ravaged his brain and changed the course of his life.

One of our first tasks as his parents was to assemble the dream team of doctors and caregivers in whom we could put our confidence, in that they might be able to alleviate the struggles that our beautiful son was facing. He had feeding issues. He had breathing issues. But underlying it all, it was the neurologic damage that didn't allow his brain to control the life-sustaining functions of his seemingly perfect body. The profound damage to his brain caused severe neuro-irritability, and it was intensely painful to watch.

When he first came home to us, we held tight to a little boy who did just one of two things: sleep and scream. There was no inbetween. His neuro-irritability created a helplessness in us that we had never experienced before. We went to the hospital in hope of getting some answers.

When we walked through the emergency room doors, we were already weary and overwhelmed. We were swimming in the deep, dark depths in an ocean of parental despair. We had one job, and it was to protect our son from pain. It was to keep him alive, and we were failing. Some of the dream team that we had enlisted to care for him were willing to wade in the water with us. Some dove in and swam alongside us. A few threw us a life preserver to help us get some rest. Others walked quickly past along the shore and did not dare enter the waters with us, walking away from the child who was not going to have a good outcome, who would never walk or talk or even breathe well on his own. No use in swimming in water when the odds of coming out alive were slim.

Admission to the hospital led to two weeks in the intensive care unit. Difficulty with feeding became the overpowering issue. It was a diagnosis of exclusion, each specialist declaring that it was someone else's issue. With each day at the hospital, we came more exhausted, frustrated, and desperate for answers. I just wanted our son to stop screaming, to stop hurting. We knew he would never be healthy in the way that the world would define it, but I needed to believe that we had a team who was committed to ease his pain and give him the best outcome possible.

And then one day, a new team walked in. I was alone at the hospital, and my child had finally fallen asleep after hours of screaming. Although I had met most of the team of professionals, I couldn't tell you who was there that day. The lead doctor was some-

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one I had only heard good things about. I was tired, desperate, and overwhelmed. Was my son dying? Was he going to continue to be miserable until the day he died? All of that scared and saddened me, and I felt I owed him more.

The new doctor quickly began introducing himself and the rest of the team and reminded me that I had met many of them before. There were four of them, and only one of me, and what was left of me was fragmented and distraught. As they were sitting by the bedside, the lead doctor began by telling me that my son's body was most likely shutting down. It is the words ". . . and you don't want him hooked to machines, do you?" that have stuck with me since that day. That was the moment I began to doubt the team who sat before me.

Skepticism. Mistrust. Fear.

"Hooked to machines"? In an attempt to help me understand the seriousness of my child's condition, these words were used, not out of lack of caring or maliciousness in any way, but I didn't trust anymore. It was not the devastation of the news that I was receiving that day, it was that I did not feel I was given the options in an honest and unbiased way. This doctor didn't know my son and he didn't know our family. He didn't know that we had a young daughter at home who required a ventilator. He didn't know we understood what it meant "to be hooked to machines" in a way that wasn't shown in the latest television drama. We lived it with a child who had a beautiful qualify of life. It did not mean that the choices that we made for our daughter would be the same we would eventually make for our son, but it was important to us that we feel a sense of trust in the team who was asking us to allow a do-not-resuscitate/do-not-intubate (DNR/DNI) order to be signed for our son. I lost that trust instantly when I was not given all the options of care for my son that day. The words "hooked to machines" told me more than the doctor could have ever imagined. I heard a biased explanation intended to persuade us to make a decision that he felt was best for our child. But I needed to be given all the options that were open us as we moved forward. I needed someone to give me honest, accurate, and unbiased information so that we could make an informed choice that day. That opportunity was lost.

Not only did I feel overpowered by this doctor and his team, I felt the loss of not having someone by my side to help me accurately hear what was being said. I wished that the news could have been delivered at a mutually convenient (or ultimately inconvenient) time for all involved. Making this decision was not an emergency. I wished that I had had time to make sure my husband was there to hear this, so that I didn't need to be the one to summarize the news for him. In such an emotionally challenging time, I no longer trusted myself to accurately convey information. My son's father deserved to hear this news from the doctors, not through me.

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Shortly after that encounter, another doctor was able to find a combination of medications that eased my son's pain. When we left the hospital, we did not leave with a DNR/DNI order in our hand. We did eventually regain the trust of these doctors who earned our trust with their honesty, knowledge, and respect for us. Over the years, those doctors got to know our son well. They took the time to get to know our family, too, and they understood our values, weaknesses, and our strengths. They were not afraid to share all of the options that were before us when deciding what was best for our son. They helped us to listen to our son's voice despite the fact that he never spoke a word. In the end, we felt our son's life was honored and respected by his healthcare team.

Undying love. Overwhelming grief. Unexplainable peace.

Six years later, with guidance from our team, we made the decision that we didn't want to be in a hospital when our son took his last breath. We knew that extreme life-sustaining measures were not in his best interest. When our son took his last breath, in our arms, in our home, with his family surrounding him, it was exactly as it was meant to be. He died in a way that honored his life and beautiful spirit.

Delivering difficult news is never easy, and it doesn't always go as planned. But, if done in a spirit of compassion, honesty, and lack of bias, a family's right to choose what is best for their child can be honored. We fought for our son's dignity in life, and now live at peace knowing we made the best informed choice for his death. We are free to grieve his unthinkable loss without the doubt that we had not been presented all care options. Our family can grieve in peace.