

A PIECE OF MY MIND

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Love at the End of the Beginning of Life

At 2 o'clock in the morning, as the situation went from bad to worse, I stepped away from the bedside to call the parents.

Looking back, I knew the prognosis for the 6-month-old girl born with a severe congenital heart defect had never been good. Shortly after birth, her lungs had gotten very sick. Her condition had deteriorated gradually, every day being either no better or perhaps a bit poorer than the day before.

But in the way that incremental bad news can accumulate yet go unacknowledged—that is how we came to 2 o'clock in the morning and the sudden realization that an inevitable crisis had been unfolding slowly for weeks on end.

The year was 1998, and I was the third-year pediatric resident staffing the intensive care unit. I had been caring for this little girl with her curly wisps of blonde hair for three weeks and had gotten to know her parents. From the first day I met her, I had embarked on a journey with her and her parents into this strange world of high-technology illness, with all of the wonders and distractions that medicine has to offer, trying to avoid yet constantly circling around the worry and fear of what might happen.

Now the center of that circle was here. I spoke with the attending physician covering the service for the night. We agreed on the plan. I phoned the parents at home. They lived nearby and arrived within minutes. We huddled next to their daughter's bed.

"She doesn't look good," the mother said. "She looks really bad." The father nodded in agreement.

"Let's go find a place where we can sit and talk," I said. I walked the parents across the intensive care unit, through the open door of a small conference room, and turned on the light. We sat down in chairs, facing each other.

I tried to clear my mind, to step away from the intensive care alarm bells and blinking lights, to get centered on being right there with these parents who were so devoted to their baby girl. I knew I first wanted to make sure they understood the situation that their child was in and then to present as forthrightly as I could the decision that they were confronting. I had not been trained about how to have these conversations, other than watching more senior physicians talk with parents in the midst of an emergency. Most often, these discussions centered exclusively on the medical facts about the child, the diagnosis and grim prognosis, some presentation of the pros and cons of different treatments, all focusing on making a medical decision.

But was making a medical decision the heart and soul of the challenge that these parents faced? Our clinical team did have to know what to do, so we needed a decision. These parents, though, confronted

the illness of their daughter in the intensive care unit, a place for taking nothing for granted, where all of life's unwritten promises about how childhood will unfold are suddenly erased: All the standard baby accoutrements are replaced by tubes and wires and medications; the bassinet at home remains empty. For days and nights on end, I had watched them stand at her bedside, stroke her, bring her embroidered blankets, surround her with pictures of her brother and sister, sing to her. For them, the medical decisions were part of a bigger challenge: How do you love your child in such a world?

I looked at the mother and father and began.

"I have seen loving parents decide that the best way to love their baby is to escalate care, seeking to prolong life. For your baby, this would mean switching from this ventilator setup, with the flexible tubing, to a different kind of ventilator that requires a rigid tube between your baby and the ventilator. This oscillator ventilator is often able to provide better oxygenation for babies. Doing this will not fix your baby's heart, but might help for a while, and perhaps your baby will start to recover."

I paused, taking stock of how the parents were reacting to what I was saying; they looked tired and sad yet fully focused. I continued.

"I have also seen other loving parents decide that the best way to love their baby is to focus on the baby's comfort, moving away from intensive interventions, knowing that by doing so, their baby may die sooner but hopefully will live better for the period of time before dying. For your baby, this would mean staying on this ventilator setup. This won't help with the oxygen problems, but it will let you hold your baby in the chair next to the crib for as long as you want. You can call other family members to have them come in to visit. If we see any signs that your baby is uncomfortable, we can give her medications to help.

"I have seen loving parents move down both of these different paths. I will support you either way."

As I finished, the mother and father looked at me, their faces lined from months of hope and sadness, and then turned to each other, and without a word embraced. I diverted my gaze to the floor. Then the father said, "Can you give us a minute alone? We need to talk."

I gathered myself and left the silent room, returning to the infant intensive care unit and the bedside of my patient. She appeared asleep, her brow unfurrowed, showing no signs of distress. Her hair was combed smooth, and, as I drew nearer to examine her, the lily odor of soap and baby mingled about her. But this interlude of calm, even if I closed my eyes to the dusky blue hue of her skin or the low oxygen saturation level reported on the monitor, would not last: the

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crisis was building and could not be averted, no matter how much I wished otherwise.

A few minutes had passed when the parents walked up behind me. The mother spoke first: "We want to hold her."

The father spoke next: "We just called our families and asked them to come in." Then he said, after a pause, "Can we also have the chaplain come to say a prayer?"

What happened years ago in that small room has shaped not only how I care for children with severe illness but my life. Through my work as a general pediatrician and palliative care physician, I have been privileged on so many occasions to witness parents

demonstrate the depths of love toward their children, to feel their determined courage to walk down such difficult paths.

How do we best support parents when they confront these almost unimaginable situations? On the one hand, the task is simple: be straightforward, clear, balanced, compassionate. Stay focused on helping the parents as they search for a way to be the best parents they can be, on their own terms, for their ill child. On the other, being fully present in the midst of such strong emotions and stress is a challenge worthy of a lifetime's determined effort. Yet even amid the tumult of some of the worst that life puts in front of us, some of the best that life offers also blooms.

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The aim of love is to love: no more, no less.

Oscar Wilde (1854-1900)