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Guest Voices



(Dreamstime/Patricia Smith)

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"Redirection of care" is the phrase we use at the neonatal intensive care unit (NICU) when a family has decided that the most loving thing they can do for their baby is to let them die. It is a gut-wrenching decision.

In many cases, the medical providers know early on that it will be the best decision a family can make. Usually, though, the family needs time to get there, to accept that this ending is the most peaceful one for their baby. Working as a hospital chaplain, my job is to help them see this decision as an act of love.

If this is their only child, mom typically sleeps on a small couch next to their baby for weeks. She shuffles from the hospital room to the family bathroom, takes quick showers, talks to her sister on the phone.

If they have other children, mom trudges to the hospital every morning and watches over her baby until she must pick up her other children from school. She wakes every three hours to pump milk for a baby that may never drink the frozen bags of breast milk stored in the freezer.

When the leaked draft of the Supreme Court opinion regarding *Roe* v. *Wade* came out last month, I immediately thought of these babies. These weeks at work, the word "viability" is buzzing in my mind with each patient encounter. I don't think many people outside of a NICU have a full understanding of what "viability" can mean. Have you seen a baby born at 23 weeks?

The first time I saw a newborn this young, it was startling. Underneath the tubes and lights and machines was a bird-like creature not quite ready for this world. I thought I might be scared, taking that first peek, but I wasn't. The tender care of the nurse, the gentle gaze of the mother; all of this love in action helped me to simply see a baby. A well-loved baby. Once mom was ready to redirect care, we baptized him. And then he died.

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It has been about a year and a half since I transitioned from university chaplaincy to hospital chaplaincy. Before, I used my lens as a lay Catholic, Jesuit-educated chaplain to help young adults discern whether or not to change their major from biology to psychology. We talked about death and careers, families and religious

rituals. Rooted in my own identity, I took pride in my ability to meet students exactly where they were on their faith journey.

Now, my spiritual roots stretch deeper as I accompany parents on the darkest night of their lives. My branches are heavier with the decisions they must make, the questions they explore, and the consuming grief they carry.

Sometimes I offer a baptism. Sometimes I pray the rosary with them. Often, I just pat their baby's feet gently, assure dad that this is a beautiful baby boy, and say a prayer to myself as I leave the room.

Many babies — most! — get to go home at the end of their stay in the NICU. But when they do not go home, when their bodies stop working, I am there.

For weeks, I have been reading articles and social media rants offering varied thoughts on the impending *Roe* v. *Wade* decision. To me, many of these opinions are lacking nuance. There are strong opinions, yes, but where are the complexities of real life? The complexities women and families must navigate every single day?

Last year, I had the privilege of talking to a family as they decided to redirect care for their 6-year-old daughter. When mom got pregnant at the young age of 19, her physician told her that her baby had medical complications that were most likely incompatible with life.

Her family and friends told her that God would work a miracle. "Have faith!" they assured her. "God is in charge!"

Sometimes, there is a miracle. Sometimes you read the stories of a misdiagnosis or a baby born shockingly healthy. Or one who can overcome their medical complexities with a little time. These stories, praising God, are shared widely. They feel very good to read; I am so happy for these families.



(Unsplash/Hush Naidoo)

For this mom, there was no miracle, not in the traditional sense. Her daughter was born early with complex medical needs and required 24/7 care. And mom felt like her faith must have been too small, that her God had not chosen her for a miracle after all. For six years, she tended to her daughter's tracheostomy and gastrostomy button. She lovingly prevented bed sores by carefully bathing and turning her daughter regularly. The family sacrificed vacations and date nights and family reunions and any chance to leave their home in order to care for their daughter.

But her daughters' vision had started to deteriorate, and she was not able to hear, either. She had never crawled or walked or talked; she rested in a bed all day, every day. Now, she could not see a television screen to watch cartoons or the silly face of her big brother.

"She's starting to weep," her mother told me. "I had severe postpartum depression after my first son was born. When she weeps, she cries like I used to when I wanted to kill myself."

The night of my visit with mom and dad, their daughter was hospitalized with acute pneumonia. It was her third or fourth hospitalization this year. They had never spoken these words out loud, not to anyone, they told me. Not even to each other, not until a few days prior. But they were thinking, "What if we don't re-intubate her this time?" Which, put another way, means, "What if we redirect care?" Which, put another way, means "What if we let her die?"

We visited for three hours, and the Holy Spirit was there, too. Their love for this child was so intense it was nearly palpable. Every decision they had made to keep her alive, to keep her as healthy as they could, was rooted in love. And it was painful but important for them to believe in their bones that this decision was rooted in love, too. That by declining extraordinary measures of artificial life support and allowing for a peaceful death, they were honoring the dignity of their daughter's life in the most sacred way.

What is a miracle? What is viability? What is dignity? This essay is not an answer, it is an invitation. As people continue to debate abortion care in the U.S., I invite you to imagine walking the unit with me. Please take small slow steps. Keep your eyes open, your heart curious, your spirit gentle. Imagine the conversations a mother is having with her partner, her sister, her best friend. Give her space. Root yourself in your faith, but know that the answers to these questions are not black and white; they cannot be black and white.

As Dorothy Day reminds us, "Life itself is a haphazard, untidy, messy affair." May God give us wisdom as we navigate this chaos.