



The Ignorance of Youth

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When she was rolled into the neonatal intensive care unit for the first time, she was wearing sweatpants and her high school senior class sweatshirt. Recently graduated, exhausted from delivering, she was everything that I had been taught not to be: a teen mom, married before attending college, raising her family in her parents' home. Her husband was nearly as young as she was. Dressed in jeans, his sweatshirt displayed the logo of a band that I couldn't identify.

They entered the NICU as many parents do, drained, eyes etched with worry, yet brimming with anticipation to meet the child who had been whisked away from them. Their daughter had developed respiratory distress shortly after birth. She had blue eyes, a wisp of blonde hair, and a face that, even hidden under her tiny CPAP mask, didn't quite resemble the other babies around her. As a fourth-year medical student, I couldn't immediately place her features, but the genetics attending whom I consulted over the phone knew before I had even finished my first sentence. Their daughter had trisomy 13.

Like other infants with the same genetic abnormality, the life before her would almost certainly be significantly shortened and filled with a myriad of medical complications. With each passing day, our team did

its best to thoughtfully, yet firmly, lay out for the family the many challenges ahead. We were frequently met by a quiet mom and a fiercely optimistic father, prompting a common question: How were these parents ever going to make the informed decisions about their child's future that we needed them to make? I struggled to relate to them—two very young parents, sometimes with their older toddler in tow. The older child arrived in a whirlwind of sniffles, snot, and sass, prompting nurses to preempt her presence with an extra layer of hand sanitizer and hustle her back out of the unit after a quick moment spent admiring her new baby sister.

Over the course of the next several weeks, the baby did face many setbacks. She was intubated, extubated, and intubated again, each time failing to breathe comfortably or consistently for a prolonged period on her own. There were two options—surgically place a tracheostomy in order to more comfortably prolong her life with mechanical ventilation, or extubate her with the intent of providing comfort care for her remaining time. The more time I spent caring for their daughter, the more her parents turned to me as a source of updates and information during their visits to the NICU. Despite our growing rapport, I still judged them for their youth. I constantly wondered how much of the information we

communicated they fully understood. I feared they would make decisions for their daughter without fully understanding the consequences.

I was relieved when, after a particularly long family meeting, they finally decided. The questions they asked showed a sophistication now that they hadn't before, and showed us that though they were often quiet, they had been listening. They thoughtfully articulated their goals for their daughter, and ultimately decided to decline a tracheostomy and remove their baby's breathing tube.

I stayed late the night that we extubated their daughter. We had moved her to a private room, and one by one her family came to spend time with her. I stood against the wall, hoping to blend into the surroundings as seamlessly as possible. Her oxygen level quickly dropped when her endotracheal tube was removed. I wasn't surprised. I'd seen her struggle in this same way many times over the past several weeks. The attending quickly passed the baby off to her mom and dad, who held her calmly and gently as she took her final breaths, the rocking chair's gentle rhythm far outpacing her breathing at the end.

I had never watched a patient die before. Still standing with my back

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against the cold glass door, I was struck by the headlights scattered along the main road in the distance as I looked out the window. Our sleepy small town suddenly seemed to brim with a disproportionate level of activity for the late hour. The cars outside drove on, with no knowledge of what was happening in that moment, just as I had driven those same roads countless times without any thought to the families whose lives were forever changing, just yards away. Reflected in the glass, I could see two parents, whom I had judged so harshly, quietly rocking their daughter as she passed

peacefully away, almost as if they were simply soothing her to sleep. I don't know if their maturity and wisdom had been there all along, or if the NICU had forced them to grow up quickly. Either way, I had been wrong.

Years later, I frequently take myself back to that room. It gives me momentary pause when I am full of doubt, when my faith in a family or a patient is dwindling, when I need a reminder to give someone space to exceed my expectations. I am older now, but never fully immune to the biases of my youth.

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