

## Seeking Clarity

By Liz Morris

After four years of bantering with medical specialists, I'm surprised by the twinge of embarrassment that vibrates in me as I hand-off with the Chief Resident caring for my son in the Pediatric Intensive Care Unit. Maybe it's because the doctor looks like George Clooney in his ER days, with a similarly masculine name to match. Perhaps it's because the question I need to ask exposes my shortcomings as a mother and caregiver. But I must know. It is seven PM. He is about to turn care over to the nighttime Resident, and I am about to switch shifts with my husband. We've got to have the story straight. Attempting a casual tone, I ask, "This may seem like a silly question, but we recently found a bit of mold in one of our windowsills, and I haven't gotten around to cleaning it out. Could this be the cause of infection?" Blessedly, the doctor assures me this is highly unlikely, and even tells me that his place had mold once. His candor consoles me. It's likely not a fungal infection we're dealing with, so it's likely not my fault we're here. I am relieved. I cannot bear more responsibility.

We go on to discuss the current care plan for my son – four years old and absolutely where he needs to be. Respiratory infections can become very dangerous very quickly for kids with complex mitochondrial disease. This is our first time hospitalizing him for respiratory concerns, and our first time in the PICU – though by no means is it our first time at the hospital. We're covering all our bases. The doctor and I land on a shared understanding of the care plan through a series of questions I fling at him with the precision of an investigative reporter.

Together, we agree that my son has an infection of unknown origin in his lungs. No COVID, MRSA, or RSV. He is negative for all standard viral and bacterial panels that may be the culprit. He's on broad-spectrum antibiotics to get ahead of any potential bacterial causes. The team will try to take a culture from his sputum later in the evening to screen for rare bacteria – it's likely the source of infection. No sign of fever. My son will stay on BiPap until his effort of breathing improves, with deep suctioning and vest treatments every four hours at minimum. I've given the team permission to intubate and resuscitate if needed. We're withholding food from his G-tube to eliminate any potentially confounding metabolic influences, but he'll receive continuous hydration and his regular medication regimen. His metabolic labs are all stable and his medical home team is closely looped in.

This is a good plan. I feel good about this. (In retrospect, it feels bizarre to have felt good about a conversation this dire, but at the time, it felt like progress.) I feel even better when the Chief Resident tells me, "I really like talking to you. You definitely know your stuff!" This recognition feels like a lifeline, and I chuckle, "Well, it's my job!" My son has been medically complex and severely disabled his entire life.

My husband and I have managed the vast majority of his care at home, without nursing support, which has given us all a beautifully calibrated yet exhausting quality of life. I'm the parent who dives right into clinical conversations at every outpatient appointment or inpatient stay and, when necessary, prompts explorations of alternate approaches. I'm the parent who has read and dog-eared Julie Hauer's *Caring for Children with Severe Neurological Impairment* like a sacred text. During a previous hospitalization for abnormal seizure activity mere weeks prior to this particular PICU admission, I asked the Resident neurologist if he wanted the "run-down," and when he said yes, let it rip like a fire hose. I summarized four years of chronic medical complexity and three days of acute shifts in baseline in under two minutes. Afterwards, he exclaimed, "that is the best patient summary I've ever heard!" The several other care team members in the room nodded in agreement, and I believed them. I still do.

It's ridiculous, then – this surfacing shock at my son's death that night in the PICU. The first cause listed on his death certificate is "Pediatric Acute Respiratory Distress Syndrome." The second is "mitochondrial disease," the chronic genetic illnesses that made him so susceptible to his acute cause of death. I can't stop spinning on the tensions that exist in chronic and acute spaces, and in particular, the spaces of grief following a medical crisis.

I *chronically* knew my son was going to die young. No clinician had ever told me this, but they didn't need to. Beyond the mountains of medical literature I read to understand his likely disease trajectory lay my intuition as a mother who adored her son. I have video of him at seven months old, asleep on my bed in darling yellow ducky pajamas. I narrate how sweet he is, and how much I love him. My voice catches with tears as I tell all future viewers that he has stopped eating enough on his bottle and is losing weight. This is right after the first of many seizure medications to treat infantile spasms will fail, and shortly before we learned he had gone blind from optic atrophy. This moment, gazing at my perfect creation, the best friend I had made for myself, was the first moment I let the life-limiting nature of his disease fully settle in me. It burrowed deeper and deeper as time passed and his symptoms progressed. Not a question of if, but when.

Somehow, I also *acutely* knew that my child's death was drawing near. Weeks before he died, I began conversations with my husband about the need to consider a transfer from palliative to hospice care. The only way I could justify this to him was *not* that I wanted to begin those conversations, but that I felt intuitively *pulled* to start them. Days before my boy died, when his fatigue had been particularly severe, I told a dear friend that I suspected his body was beginning to shut down. And the day he died, when we had the option to put him on ECMO after attempts at mechanical ventilation failed, I knew it was not the answer. I understood that his body was done, because the synchronicity that existed between us told me so.

Yet here I am, eight months out from his death and newly immobilized by grief. Whatever understanding I had about my son's life and death from a clinical perspective is fading in light of what I'm learning about my life without him. How dull it feels without his voice, his softness, or his warm weight on my body. Whatever pride I took in my medical and caretaking expertise feels futile, unearned and obnoxious in contrast to the joy and generosity of spirit he exuded. My intellectual understanding of his death evaporates in the howling hole of his absence. This feeling here, now, is protest.

I rage that I was unable to love him towards death the way I had loved him towards life. I'm devastated that I had to scrutinize his existence with the objectivity of a clinician that, at the end, overtook any opportunity to simply be his mama. A mama that would immediately rail against his death, rather than choose it. A mama who's first and foremost thoughts of her child could be his voice rather than his airway. A mama who could focus on the tender feeling of holding him rather than the physical labor associated with his immobility. It's taken significant time for the medical mama in me to release the reins in grief. Now it's just me in the saddle, a mother without a child, and I can't find my footing. In the hardest moments, I cling to my profound gratitude for the dozens of medical providers who treated me like an equal in my son's care. Those who stood with me in difficult conversations and decisions and helped me be a powerful medical advocate his entire life. It's healing to know I got that part right – though for the foreseeable future, I am anguished that I had to.

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**Liz Morris loves exploring complex questions. Her professional experiences in project management, librarianship, and community development prepared her well for her favorite role as mom to Colson, who has been impacted by mitochondrial disease since birth and inspired Morris to face the complicated aspects of his life through writing and advocacy. She serves as a family advisor at Seattle Children's Hospital and is a volunteer ambassador for the United Mitochondrial Disease Foundation. Morris is committed to helping families find the information they need to help them live well in the face of life-limiting illness. She is a 2021 Blogger-in-Residence for [Courageous Parents Network](#), whose mission is to empower, support, and equip families and providers caring for children with serious illness. Find Liz Morris on Instagram @mrsliz.morris**