

Time: A Mother's Plea

Angelle L. Klar

ABSTRACT

"Time: A Mother's Plea" is the sensory reflection of a provider who traverses the 11-month intensive care hospitalization with a mother following her son's hypoxic brain injury. It is written in the first-person narrative of the mother. The experience provides insight into the challenges of perspective, empathy, and ethics faced by clinicians when a family says, "I need time." Hearing the words naturally begs the question, "How long?" with all of the associated implications to clinicians and family alike. While some may consider withholding medical treatment as morally equivalent to withdrawing, this mother does not. The author hopes to suggest that the provision of time, in the context of well-defined goals of care, is an active process . . . for as long as it takes.

TIME WAS . . .

Another day dawns during my commute from work past acres of farmland. The morning sun peeks over the horizon and casts a faint glow over the evenly spaced rows that merge, then

evaporate in the distance. I think of my boys and wonder if they may still be sleeping. As I head in the direction of my mom's, I strategically plot the logistics of getting the kids from her house, into their three car seats, loading their bags, the trip home, and then the slow journey with them up the stairs once we reach our complex. I yawn at the thought, so my mind enjoys one last moment of silence, as what is the end of one day is also the beginning of the next.

We arrive home and make our way through the threshold where the weight of the load causes us all to collapse on the floor. Giggles ensue and off they go, as if just set free at the starting gate. My eyes land on the sofa across the room. It was a gift from my mother that has borne witness to chaos and offered refuge as, in my early twenties, I became a young, single mom. It takes a minute to muster up the energy to relocate there with my coffee. As I settle into it, I rest my cup on the cushion next to where my head lies. There's a little tear that exposes just enough of the padded interior to keep my coffee from sliding away and spilling.

I close my eyes with no intention of actually sleeping. I've memorized this apartment by now, and I'm able to tell exactly where each of my boys is with my lids sealed tight. I hear

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them wandering around as cabinet doors swing open and shut, but I do not worry. There's just two old cribs that sit side by side in one room and a mattress on the floor in the other.

Just then, the light from the opening fridge is bright even behind my closed eyelids. I hear a faint whimper reminding me that to actually sleep is not yet the plan, so I sit up. The oldest is not even three years and attempting to prepare his own snack. Weary, I crawl over to the kitchen and snuggle up behind him to peek inside and help him choose. He settles on a cup of pears, and so I pull out three.

"Who wants a snack?" Escalating pitter patter announces their arrival, and we assemble in a circle for our picnic on the kitchen floor. As their three bellies begin to bulge, my little one rubs his eyes as if exactly on cue. We head to the first room and, without even turning on the lights, I lift my big boys into their beds, and they bundle up in their blankets. I turn to head to my room and see my baby has scooted himself nearly there. When I pass him by, he bounces up and down on both knees with his arms held high, so I lift him up to join me on my mattress pushed up against the corner walls. His favorite blanket awaits him. He tucks his thumb in the small hole rubbed through the corner near the trim and into his mouth it goes, with the edge of the thread tickling his nose. Gazing into his eyes is just as good as counting sheep, and I am soon drifting off to sleep.

I awaken to deafening silence. I have done without an alarm since becoming a mother, now accustomed to the children waking me instead. But that hasn't happened. While still lying down, I brush aside the blankets around me to feel for my baby, but he is not close enough to reach. I sit up to stretch further. As I grasp his chubby leg and draw him into me, he remains motionless. I flip him over and notice bubbles spilling from his mouth and nose, and his open eyes stare straight

through me. I am initially paralyzed, and then everything is an inconceivable blur.

I can still feel the weight and warmth of him lying limp in my lap as I speed to the hospital. I see the rush of people to our car as I pull up the ramp screaming with the windows down. I sense the emptiness in my arms once I hand him over, but I remember thinking "Finally, everything will be alright." They rush him inside, leaving me alone for a moment. I pause and take a breath before heading into the hospital for the first time.

Off in the distance, there is a rush of activity, so I walk closer, feeling that has to be where he is taken. There appears to be someone on all sides of him, and one on top. Just then, in the space between all those bodies, I see his little arm closest to me fall from the table on which he lay and dangle for a moment before getting scooped up again to rest beside him. My mind keeps going back to the sway of his lifeless fingers as the very moment when I know for certain, nothing would ever be alright again.

TIME IS . . .

That day we are sent to the children's hospital in the city with the hope that they will be able to offer more. One day turns into the next, then the one after that, and it is not long before I begin to await the passage of time.

My son is positioned on his back with his arms straight down by his side, and he can't turn in his sleep. The thin tube in his nose is connected to the pump that feeds him, but he can no longer choose

his own snack. The plastic tube in the corner of his mouth is taped to his lip and attached to the machine that breathes for him. His eyes remain closed to the world around him, and I have not seen them gaze into mine with purpose or recognition since that very moment we fell asleep face to face. I watch the second hand of



the clock in his room pause over and over and over. I cannot hear the tick tock, but the imagined sound rings in my mind as loud as the swoosh of the ventilator. My mind, body, and soul remain caged in the solitude of this tangled mess.

The first week, a doctor comes in alone to explain about the brain injury. He tells me we need to let my baby breathe on his own without the machine. They don't expect him to breathe without the tube, and, once removed, don't plan on putting it back in.

I say "I need time."

The second week, I am escorted into a conference room where I sit in the middle of a group of doctors, and it is all explained to me again. Days pass. The room and characters change, but the message remains the same no matter which words are chosen or where they are spoken. Everything is focused on that tube.

I repeat, "I need time."

The third week presents a new team of doctors. They stand at the side of his bed and explain that some patients are able to live for some time on a ventilator with a trach and even at home, but because of his brain injury, my baby can't. As I imagine this possibility, I think of all the times I have dreamed of having him home, but not like this. If he is to come home, he has to resemble my baby boy. I dare not voice this aloud.

I am initially overwhelmed with the supportive presence of the hospital staff. But as time passes, routine sets in. I begin to notice fewer people enter his room, and only when there is a task to complete. One nurse after another changes shifts and greets me. They suction him and change his diaper and feeds, but it appears there is less and less for them to do. It isn't long before I feel them watching the clock with me. I soon feel that the only thing the children's hospital has to offer is for my son to rest in peace once I agree to remove the tube.

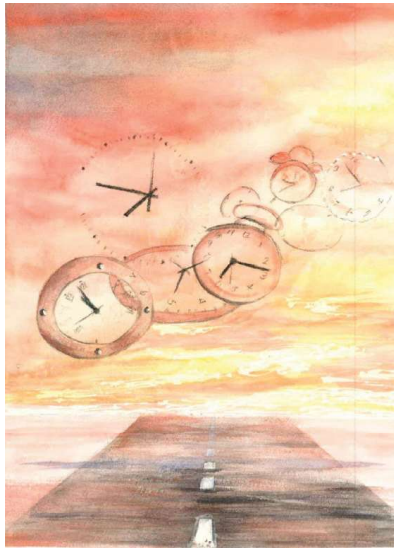
My mother takes my other boys in, and I do not return to the job that pays for that apartment. I do little beyond exist in the shadow of this hospital bed for three weeks straight, seeing my big boys only when family could spare the gas to bring them the distance for a visit.

After these initial weeks, I receive a call saying my big boys have been taken from my mom's house to live with "someone who can take care of them better than I can." The state fears this will happen to them too. They say I need to "learn how to be a mom." I rise from my son's bedside, walk out of the hospital doors, and return home to begin the process of untangling.

The hospital begins to call and to check on me, but I feel them watching the clock, wondering where I am and why I am not there. The only questions I know to ask are whether his face is clean, has he moved, or has he triggered the vent—those words I learned at the hospital. I have come to feel angry when his face isn't clean, which offsets the anger I am not justified in feeling over him failing to move or to breathe. About two months after the nap that day, I receive another phone call from the hospital. This one lasts a little longer, and within the time and space left for silence, I begin to open up. I share of my life and my family, becoming a mother once, then again and again, and each decision I made that eventually brought me to the night shift at the plant that resulted in the fatigue that led to the nap that very day. The tears start and do not cease. This is the first of many conversations when I am able to share my thoughts, my feelings, my heart, and my regret, but at no time do I agree, regardless of how it is suggested, that the tube may be removed. That tube signifies what time is. Removing it represents what time will forever be, and I am not prepared for that.

So I repeat, "I need time."

I schedule parenting classes in the city so I can visit the hospital. When the doctors learn



that my children have been taken from me, they write letters on my behalf, but no words erase the guilt. I am careful to avoid the mirror. I am even less able to meet my own mother's eyes.

After four months, my boys are returned home, and I begin to learn a new way of life without the baby. My family is only partially intact, and part of me remains in the city. I still can't allow them to remove that tube.

My visits become separated by days, then weeks. Each time I arrive, I dread what I will find on the other side of those hospital doors. I learn to head directly to the lady at the front desk, first, to find the baby's current location. His bed number changes regularly, as he is shuffled around amongst the "real" ICU patients. They call it "staffing." After being told the bed number, I hang my head low to avoid the sting of their stare and find the new shadow beside his bed where I am safely concealed.

After several months, I am forced out of the shadows and ushered again into the same conference room where I sit alone among a large group of doctors. I begin preparing to hear the same song ringing in my ears, but, today, the tune is less familiar. There is mention of ethics. I worry this means they will force me to remove the tube. They wonder if I want a second opinion. I don't. After all, I say, "Isn't this the best hospital, the only children's hospital around? Aren't you the experts?" I believe what they have told me, for I have seen it with my very eyes since the moment I turned the baby over in bed that day. As much as I know he can't live like this forever, I can't end his life. They speak of "suffering," but, as I picture him lying so still, I wonder if at this very moment he's truly suffering? He looks the same as he did yesterday and the day before. So if he is not dying right this very minute, why remove the tube?

As they talk, I wonder about the legal implications, and I don't want them involving the law again now that I have finally gotten my boys home. I feel as if the hospital just wants this all behind them, and, somehow, I hold the power to make that happen. But I can't and won't remove that tube. A choice like that will define my life in a way more permanent than the nap that day

has already defined me. When I learn they won't force my decision today, I realize I have been holding my breath, so I sigh. I also understand they are no longer posing questions to me. They will continue to care for him just like they have been, but they won't increase the ventilator or the size of the tube as he grows. Somehow, that feels okay, because today, the tube is big enough and long enough. This doesn't have to be my choice. They give me more time.

TIME WILL BE . . .

A new normal emerges. The hospital calls bother me less, I settle into visiting when I am able, and I take the next breath easier than the last. Days and, sometimes, weeks pass between visits. I notice his teeth. I rub my finger across his gums, and I think how I will never see their imprint on the wooden rail of the bed next to his brothers'. I see how his clothes shrink as he grows, and he wears adorable new clothing that I have not bought.

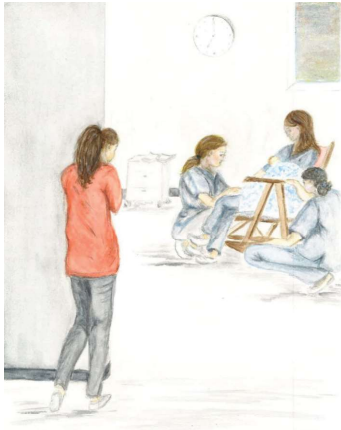
As he grows, I also realize his tube is becoming smaller.

I notice the pages of his bible in his bed turn as if someone is reading of Him. He has a new blanket woven in the colors of the sky. At first it is small, but with each visit it grows, as if someone is sitting there creating it especially for him. He no longer belongs to just me.

One day, the sound of the phone ringing from the hospital startles me. "Come now," they say. I sense the tick tock of the clock again with each passing mile, and I am not able to get to the hospital quickly enough. Although I have imagined this moment since the day I last looked into the baby's eyes nearly a year ago, it does not feel at all like I thought it would. Today does not look any of the ways I imagined it last week or the week before. Today isn't as I feared it would be when I considered today last spring, or last winter, or the fall before. All that has changed is time.

Today, I stand at the door of the baby's room that is full of people surrounding him with reverence. He rests gently rocking in the arms of one I know well, whose gaze I avoided

for so many months. I know the face of the one holding his hand, those kneeling down on the floor beside him stroking his feet, the ones leaning softly against his bed. I feel their sadness, and the tears that we share bring me comfort. They rise, allow me to sit and hand the baby to me so I can rock him for the last time. Today is just as it should be, and it couldn't have come to be one day sooner or in any other way. I just needed time.



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