

Foster Care: Heroic Measures

written by Guest Contributor | June 6, 2019



On a bright Wednesday morning in March, we leave for daycare and work because that is what we do, even when we've spent the evening in Trauma One of Children's Hospital because WD, my two-year-old, had a longer-than-usual seizure. We were home by midnight; everything seemed under control. Why wouldn't we go about our day?

We're only a few blocks from home when WD, strapped in his car seat, starts making a sound that's somewhere between a gasp and if someone punched you in the gut. His face turns red and his lips smack. Bubbles form around his mouth and his eyes stick to one side. I set the stopwatch on my phone and say reassuring things and try not to crash the car as I watch him in the rearview mirror. We drive a mile past daycare to Children's, where I park illegally and they put us back into Trauma One.

I watch them; I watch WD. Though WD is sturdy, his veins are whisper-thin and roll away to protect themselves. A heating pack helps as does a small, bright light held against his skin to show the way. Intramuscular Versed, a benzodiazepine similar to Valium, buys time.

They inject Versed into his thigh. They work for an IV. They administer Ativan through that IV and then a second-line med. Eventually—forty-five minutes since it started? an hour?—the seizing stops and WD sleeps.

Upstairs, on the unit, the admitting nurse goes through the usual questions: *who lives at home?* Just the two of us. *I have this name for your emergency contact?* That was our caseworker, but I adopted WD last summer. *What therapies does he receive?* Occupational, physical, vision, hearing, and developmental through Early Intervention and daycare. And then a new one: *does he have an advanced directive?*

Oh.

It has not occurred to me that a toddler, even a medically fragile/complex one, might have an advanced directive.

No, I say, and she moves on to the list of his daily medications, which I

answer by rote while the rest of my brain stalls, working this new idea. The nurse's question collides into the questions I have been asking and worrying about for two years, ever since WD came into my life. Questions that other people ask me, too. *What is WD's prognosis? What does "medically fragile" actually mean?* And the one I've never been able to ask, though it hangs in the air every quiet morning in the moment before I open his door: *If I do everything absolutely right, can I still lose him?*

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A week before the hospital stay, WD began to bear weight on his legs, long enough that I could hold onto his waist with one hand and take a picture with the other, the payoff from a year's worth of time spent in a stander and a gait trainer, teaching his muscles that they exist, that they can be strong.

The day after he's discharged, "Twist and Shout" is stuck in my head. He stands as I hold his hands and twist him along with the song; we're both explosive with smiles at the simple pleasure of the song itself and mutual pride in his growth.

In the weeks following the hospital stay, he is suddenly, intensely sad. Sometimes it seems that there is nothing except his howling, which rings in my ears after he is asleep. I at first attribute this immeasurable sadness to the new anti-seizure medication he started in the hospital, but the neurologist says irritability is not one of its side-effects.

Amid this sadness, WD transitions into the older toddler room at daycare. In the hours before bedtime, he falls asleep across my torso, his hair sweaty in my neck. But he also continues to gain control over his muscles, bit by bit. He figures out how to hook his right arm around my neck and squeeze—a hug! He starts pressing his open mouth against my cheek as babies do.

We develop an evening ritual. When we get home on weeknights, he stands and I kneel in the middle of the living room. I put my arms around him and he hooks his right arm around me. I say, "We are home, and we're together." He smiles his dimple smile as he sways and presses his mouth into my upper arm or against my face. "I missed you today," I say into his curly hair. I give him a squeeze; he returns it. "I'm glad you had a nice day," I say. Or, "I'm sorry you had a hard day."

It's just a few minutes before his legs buckle. I guide his body to sit on my lap, so I can kiss the top of his head. I unfasten the Velcro straps on his shoes and lower him onto the rug. "Your shoes are your job," I tell him, and busy myself with putting away our things while he kicks his feet free. "Thank you," I say, as I pluck the shoes from the floor.

Like most toddlers, he veers between these joyful developments and unabating misery, but he can't tell me the cause; so much of the life he and I make together is an elaborate guessing game. After a couple of particularly hard

days, his nurse at daycare runs her fingers along the hard bump on his head where a shunt works underneath to mitigate hydrocephalus, even though the hospital had just tested it via CT and x-ray. She squeezes along his limbs. Presses into his belly. She suggests that he be seen again, so I take him to Urgent Care and they check for ear infections, strep throat, bowel obstruction, general tenderness. *Has he been urinating, vomiting? Does the pain appear to follow his feeds or any other cycle or wave?* The doctor taps a tongue depressor against his teeth. Nothing.

We visit his mom, his brother, his grandma. The next day, he turns three, and we have a big party with our church family. The day after that, he begins preschool.

Being three brings a newfound imperative for attachment. He's always been cuddly, but this is different, deeper. He cries when I walk away, flails his arms in the air around my phone when I become bored. He is joyfully out the door for school, pleasant while riding in the car, but when he knows my arms and my attention are available, he demands them.

I do not know if this is three or if this is his body, heart, soul, asking for reparations for the first years of his life. In order for us to meet eleven months after WD was born, the worst thing already had to happen. Worst, of course, is relative. Here, the worst is that he lost his mom, his brother, other doting women who share his facial features, his home. You're not supposed to lose your mom and your home. Not in your first year. It's easy for me to get lost in the injustice that he was placed in care. It's easy for me to get lost in the injustice that he needed be placed in care. Or in the fear that, if the worst-worst happens, he'll have lost everything for nothing. I do not know if his current distress is an opening of the bottomless ache I have heard about from adult adoptees. What if he has been wanting reassurance all along, but has only now learned how to make his wanting known?

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Out of curiosity—mild—about advanced directives, I learn their history and just how recently we've been able to try to negotiate death. In an effort to mitigate anxiety—extensive—about WD's safety, I start reading medical journals. I'm not qualified for this task. I didn't go to med school; I've never so much as looked at an anatomy book. The last biology class I took was in ninth grade, and mostly we colored while our teacher planned her wedding.

The list of risks is long: schizencephaly, epilepsy, hydrocephalus, ventriculoperitoneal shunt failure, cerebral palsy. I know this is not a scientific approach, but I plug in each term + death into PubMed as if I can combine a series of percentages that I don't actually understand and arrive at a concrete number that means something. Do I need to be 1% worried about his death? 15? 30? What would that even mean?

Even though he had seven surgeries in an 18-month period—starting when he was ten months old—and the forever potential of more, my risk list of things I worry might kill WD does not include the obvious: anesthesia, surgery itself, post-op complications. Even listing them now does not compel me to add them.

More practically, I want to know the mechanics of how someone winds up brain dead. Brain death comes up in almost everything I read about advanced directives, as if it's an actual place, somewhere more liminal than the beatless heart. I don't know what—if any—decisions I would have to make to try to avoid brain death or what I would need to do after it happened. Medical journals aren't very helpful in this regard. I read, for instance, that seizures feed on themselves and can kill you, but not *how* they kill you, mechanically speaking. Is it the brain? The heart? Something else? All I can find is a scenario from a medical textbook that offers types of medications to give as time passes as well as how to manage an increasingly frantic mother—not parent, *mother*—who eventually needs to be removed as the child is put into a coma.

In the journal *Pediatrics*, I find a graph—an inset to “Mortality Risks in New-Onset Childhood Epilepsy”—that plots age of onset of epilepsy to the age of death. The lower left-hand corner is dense with epileptic babies, quickly come and gone. WD is in the thick of the Xs, which trellis the left axis, where onset is in the first year of life and the first dash when the child turns five. On the graph, after that first dash, kindergarten, the Xs thin out, and maybe that's when I'll be able to breathe.

I become immersed in statistics, some about medical complexity, but mostly about epilepsy (seizure disorder) which further breaks down into status epilepticus (seizures lasting longer than five minutes) and Sudden Unexplained Death in Epilepsy (SUDEP). The numbers bounce against each other. Brain abnormalities occur in 3 out of every 1,000 pregnancies (not all live). Children with medical complexity are 14% of the pediatric population and account for 40% of all medical costs of the same. One third of pediatric deaths are among children with one or more complex chronic conditions. Children with epilepsy die at a rate of five times that of the general pediatric population. Optimal seizure control requires near-perfect adherence. Eighteen to 23 per 100,000 children experience status epilepticus each year. Two-seven percent of them die. The same number of people—approximately 45,000—die from epilepsy each year as from breast cancer. SIDS kills 1,575 babies annually and fire, including deaths from smoke inhalation, claims 2,760 people of all ages. Every parent learns the risks of SIDS; every child learns fire safety.

The number of people who die from SUDEP, which precisely zero doctors have mentioned to me? 2,750.

My hope is concretized information will help alleviate unbidden panic. But really, none of these tells me what to expect for WD. And all the information in the world won't keep me from holding my breath at his bedroom door.

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In July, we go out of town for a family reunion. The day is hot and the lake is cold. We sit on the sand and let the water slide up our feet. WD's not particularly thrilled by this, but he also doesn't hate it, and that's enough for me.

He's finally finished a months-long wean off of phenobarbital—a powerful, old-school anti-epileptic that has increasing long-term side-effects—and he hasn't had a seizure since the one in March that landed him in the hospital. I am under the assumption that everything is golden.

There are more than fifty of us at the reunion. My great aunt is FaceTiming my grandma, who can no longer travel, the only two remaining of their parents' thirteen children. A dozen kids run around. My mom's generation talks about retirement and mine about the challenges of full-fledged adulthood. I'm trying to talk to one of the retiree-cousins, but WD is looking weird. At first I think it's the flush of the afternoon sun creeping across his cheeks, his eyes fighting sleep. But maybe it's not that at all.

I cradle him like a baby across my lap, oscillating between listening and wishing everyone will stop talking so I can concentrate.

And then he is seizing. His eyes deviate and his lips smack, bubbles coming out.

I fumble for my phone to start the timer. When five minutes pass without any change, I put him in the car, hoping the air conditioning might help. At home, five minutes is when we're supposed to leave for the hospital. Someone calls 911, and volunteer EMS is on the way when the seizure stops at seven minutes.

Except then it starts again.

I'm mildly aware that there's an audience, a shifting array of concerned and teary faces. Another cousin, who has her own medically complex son, warns me about the local hospitals. "Don't let them run you over," she says. "Don't back down if something doesn't seem right."

The EMTs arrive, a man and a woman, and I hand them WD's emergency instruction sheet. In the ambulance, the man performs as if he learned emergency rescue via television, spitting out needle caps and yelling at the driver.

The hospital, as my cousin warned, isn't much better. There's a nearly empty shopping basket for pediatric supplies, which an older nurse shoves at a younger nurse to restock. I answer questions and watch from the side, mostly thinking that this hospital isn't home and that the adult world isn't attuned to the needs of children.

An hour into the second seizure, the electricity finally gives and WD sleeps.

My parents arrive; the doctors and nurses talk at them, even though no one in my family has experienced WD seizing. *Talk to me, see me*, I want to yell.

The attending neurologist, by way of introduction, pats my head.

My family wants to know how best they can help. There's nothing much for anyone to do now that WD is sleeping. Now is the waiting, which, at home, I fill with reading. Here, I don't know what happens next. It's most practical for them to go, though it still feels a little lonely when they do.

The doctors want to helicopter WD to a pediatric hospital, which would require a breathing tube for the transfer. But then they see rain on the radar and, on account of that, they'll take him by ambulance, no tube necessary.

I still, somehow, wind up outside of the room, the doors pushed shut.

Another cousin, a retired NICU nurse practitioner, has arrived and says, "They don't like to have parents in the room for breathing procedures."

All they've done—and I watched them do this—is put a small cone inside one nostril to maintain an airway. Otherwise, he has a hose of oxygen near his head, so I'm unclear what could be happening that I can't bear to witness. There's truly nothing else to see except him as he sleeps, which I would, in fact, very much like to see.

"I haven't freaked out," I protest, quietly angry at the separation though aware that causing a scene will only prove their point. But then the doors open and I'm handed a form to sign. People in gray jumpsuits wheel out WD to a waiting ambulance, and I'm to follow in my car.

An hour and a half later, I arrive at a PICU in a part of the state I have never heard of. WD is still asleep, pale and shivering, his breathing slowed, his oxygen dropped, and his temperature sky-rocketed.

The nurses give him meds for the fever and strip him of his clothes; they put long bags of ice under each arm. He might have an infection, so they flood his body with extensive antibiotics just in case. They need blood, CT, x-ray. They strap a BiPAP mask to his face to help him breathe, and I watch him shivering, holding the bags, his favorite stuffed bear tucked beside him. I plot how to lobby for a transfer to Pittsburgh if his shunt is failing; there's not a chance in hell I'm letting anyone other than his regular neurosurgeon open his head.

The mask on WD's face has thick straps, supported with yellow foam, going around the back of his neck and across his forehead. I stare at him and consider if he looks more like a deep-sea diver or a coal miner. I think about how quickly the decisions came for the breathing mask, the antibiotics, the kinds of things people consider when creating advanced directives. I think about the ED in Pittsburgh where the doctors and nurses balance medications and breathing. I think about how, at home, he probably wouldn't be on BiPAP because they would have been mindful. These thoughts are less about being angry or resentful and more about how medicine seems so often to

be a well-informed crap shoot. And that there's really no other choice than to trust it.

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One hundred years ago—give or take fifteen years—my great grandma had thirteen children who eventually led to our gathering at the lake. Three babies died early or were stillborn. Around the 1910s, someone gave her toddler a nickel to play with. He choked on it and died. It would be another sixty years before Dr. Henry Heimlich put forth his method for dislodging foreign objects from a person's windpipe.

In the 1930s, her eleventh child, Irene, got strep throat, which blossomed into rheumatic fever, which left her heart weakened. She died in 1940, not long after she turned ten. At the time, rheumatic fever was the leading cause of death in the United States for people 5-20 years old. Just two years after Irene died, penicillin would be made available to the general public.

How do you live with timing like that?

Today, about 5% of children with untreated strep throat develop rheumatic fever. In 2016, eleven children under fourteen years old died from a rheumatic heart. Forty-three died from choking.

I couldn't help it, I had to check: 129 from epilepsy.

I don't need to be told that a kid like WD wouldn't have hung around very long 100 years ago, but that kids like him increasingly survive birth and live for longer and longer comes up often in my reading, both as medical fact and philosophical quandary. What do we make of lives we weren't expected to live?

I think of my great grandma often, of her praying her rosary alone early each morning. I know women my age who have lost babies; I know women my parents' age who lost their young-adult sons. I see them all and how very much they hurt and what it looks like when they keep going. I think about my great grandma's loss, five times over, and wonder if she passed along to me a genetic ability to keep going, too, and if I will ever need to call upon it.

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We return home from the PICU after three days; there was no infection, no shunt failure, just an unknown trigger no longer tempered by phenobarbital. The hospital reinstates the medication on a dose higher than he's ever been on. The doctors assure me they've cleared this with his regular neurologist,

and I absolutely do not believe them.

For an icy-hot second when we first get home, I wait for WD's hug and panic that he no longer can. *He hugged you Sunday night, I remind myself, after the nurse gave him a bath, while she changed the sheets, before she hooked him back up to all his wires.* In our regular life, we hug and cuddle all the time. In the hospital, I realized I was starved for it. While I could wedge myself next to him in his bed, it wasn't at all the same as having his gangly body draped across my torso on the couch or holding his waist while he leans back to be upside-down on my lap.

That gains can be lost is significantly more frightening than the seizures themselves. Sometimes lost and regained—head/trunk control, sitting—but also simply lost—eating by mouth. For loss, there is no med school checklist of what to do next and next and next. The idea of losing his hug, losing this ritual is emotional, existential. It is one thing for a child to outgrow a ritual. Watching your children grow out of things *is* parenting. But that the ability to express affection could be snatched away—replaced with nothing—sweeps blistering terror through my core.

If WD is bereft when he loses a skill, he doesn't show it in ways I can discern. Studies on adults have shown that major events—both positive and negative—only take six months to emotionally neutralize, which is not the same as rendering them meaningless. WD is, like most children, amenable to the life in front of him. His personality is old-soul sturdy and prone to delight. Me? I am less sturdy, prone to panic as well as delight.

He can still hug you, I think. It's okay. But I can't wait for his jerked hook, so I place his arm on my shoulder. There's the slight weight of it and then his little hand presses on my upper back.

It's okay, I tell myself. It's okay. He can still hug you. It's going to be okay.

As expected, his regular neurologist lowers the phenobarbital back to three milliliters a day. This is good, except in the short term, as WD is thrown into withdrawal. He's very sleepy until he's not at all. He seizes throughout the day—one, two, three minutes at a time. He seizes in the psychiatry clinic and at a visit to his primary care physician, who pulls a random neurologist in from the hallway, who can call WD's neurologist to describe what she's seeing. His muscles jump, and I feel high-wire tight all the time, ready to be out the door. It's early August now, 90 degrees out, and I have a sweatshirt in my car just in case, because the ED in summer is arctic.

Please hold out until morning, I pray at his door before I go to bed each night—the largest leap of faith I make. In the morning, you'll be safe.

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In those summer months that I spend lost in my search for answers about the nature of WD's disabilities, about the heroic measures he may or may not need, a few children from online support groups I belong to die, as they seem to do in clusters. Each time, I am lightheaded with anxiety, my thoughts and connection to my body both obliterated. Briefly, there's also international attention on the story of a British infant with a terminal mitochondrial disease. The European courts involved in his case side with hospital doctors that a Hail Mary experimental treatment in the United States would only prolong the baby's suffering. His parents, the Catholic Church, and others disagree; the baby, they say, deserves every last chance at every last minute of life. It is, like many stories, a story about what it means to parent in the space between vitality and loss.

It's dark inside these thoughts, pressurized in my chest, and I don't understand how much so until the coalesced light of realizing that the most helpful end-of-life questions are really just helpful life questions.

Life. That's what this is supposed to be about.

The first insight comes from Jeff Beck, a doctor who specializes in hospice and palliative care, who writes that, as opposed to a checklist of procedures that a patient may or may not want, "a narrative approach provides value-centered care by eliciting understanding, hopes, concerns, and other factors affecting quality of life." I *had* been contemplating each procedure, some WD had already had, like a breathing tube, or some that continue to support him, like his feeding tube.

Beck's sentence, then, lands me at the real question I didn't realize I had been asking for the previous five months: *what makes life worth living?*

In our immediate world, there are children who can speak and children who cannot. Children who can move and children who cannot. That I cannot imagine WD without his dimpled smile or laugh is a reminder of the children we know who have neither, which are otherwise among the first gifts a baby gives his parents, right after eye contact, which WD can no longer make. What would have to happen for him to no longer be the WD I know and is that something I, he, we could live with anyway?

The greater shift comes from the Presbyterian Church (USA)'s 2016 pamphlet, "Abiding Presence: Living Faithfully in End of Life Decisions." In specifically addressing the needs of people with severe and chronic disabilities, it says, "The aim [of human life] is the creation of communities of persons who affirm each other and *the experience of a profound existential and spiritual joy* that arises from that activity" (emphasis mine).

WD was baptized into the Presbyterian Church in the heavy August heat of our non-air-conditioned sanctuary when he was two years old, two weeks after I adopted him. My pastor-friend asked the congregation, "Do you, as members of the church of Jesus Christ, promise to guide and nurture WD by word and deed, with love and prayer?" The sacrament was no less a contract for me than my courtroom oath, than the commitment of unknown duration I made when I first

picked him up from the hospital. It was the congregational promise, though, that I most treasure.

And it is WD, beautiful in his sleep, holding his bear, that fills me with the miracle of each day together. I don't think it irrelevant the number of pictures I have of him doing exactly this nor the extent to which his solid existence steadies my own.

But that's about me. Is my joy too big of an ask? What is his joy and does it make his sometimes-unfathomable losses—his home, his mom, a life untethered to medical complexity—tenable? I think of WD's charisma and the way he so fully ingratiates himself with others. The way people remember him after meeting him once. How much he seems to be genuinely pleased by these connections.

The third time WD met my grandma—our first Thanksgiving together—I witnessed their inexplicable soul connection. I had thirty-two years of reasons for loving my grandma: all the afternoons at her house when I was little, every soccer game and dance recital she attended, the way she encouraged my writing. WD mostly knew her voice on the phone on Sundays. He couldn't ask for her stories or accept an ice cream cone, and by that point she couldn't go for a walk to the playground or do any of the things with him that she'd done with me. And yet, ever since that Thanksgiving, if he was near her, he'd pitch himself off my lap and onto hers. It wasn't enough to be next to her; he had to be *on* her. He was so big, and she was so small, and I imagine that he probably hurt her fragile body, but she never said so. Instead, she would rub his hair or his back. He could have stayed there the rest of his life.

It seems very nearly ungrateful to ask if there should be something more to life than that.

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In late August, WD has his first seizure-free, good-mood day in four weeks. We arrive at a Sunday that is just . . . Sunday. He dances his legs in the tub to splash the water. After church, we walk to a playground that has a wheelchair swing, where I drink coffee and he smiles into the sunshine air as I push my fingertips against his toes. We FaceTime my mom for her birthday and then Skype WD's mom, who is at a pool party with WD's brother, aunt, grandma, cousins. They all take a turn to say hello.

In the evening, he pushes a brightly colored Mega Bloks train back and forth with me. Turn taking, his therapists say, is the foundation of communication. In a five-second span, I can see the results of two years' worth of work for both WD and his village. Gross motor to sit. Sight to recognize the train. Fine motor skills to push it. Smiling when I say, "WD's turn!" It is the most basic, wonderful childhood moment. I push it to you. You push it to me. Again and again and again.

This summer, which has already been so long, will last a while longer, and then he'll spend the better part of autumn's mornings inconsolably sad once more. He will also love his new preschool teacher and try really hard each day to impress her. I can't plan for any of it. Nor can I afford to be crushed by the fear that the hard things will always be this hard.

Instead, I give him what I can: Saturday morning sunshine at the playground, rainy evenings cuddled on the couch, dancing in the living room, so many smiles, laughter. Mornings listening to Mister Rogers. Friends who take him for who he is. Long walks and drives he spends watching the light reflecting on the car window and scenery blurring by.

Instead, I try to remember to see what I can: the way he waves when he gets to daycare and school. His skeptical eyebrow and side-eye. How he spins in circles in his gait trainer. The way he plays possum when therapists arrive to collect him and he'd rather not. His hand bumping against his chin as he signs *mama*.

Instead, I feel his face, buried in my neck; I watch him, smiling on the swing; I stand, listening for his breathing through his bedroom door. Life, as it is right now, is always going to have to be enough.

I push it to you.

You push it to me.

Again and again and again.



Amy Whipple is a part-time writer, part-time church secretary, and full-time awesome. She holds an MFA in nonfiction from the University of Pittsburgh and can be found in *Pittsburgh Magazine*, *Tonic*, and *the Guardian*, among others. She's writing a book about medical complexity, adoption, and the ways we take care of each other.

Abandonment and neglect. Substance abuse. Alcoholism. Suicide ideation. These are subjects which are prominent in child welfare and foster care; on average, foster children remain wards of the state for two years. I asked: Why are these stories uncommon despite its longstanding presence? Why is the adage “education out of the system” the emergent path to adulthood? Why have I not found a safe space for these stories from educators, administrators, foster parents, biological parents, kinship placements, adoptees, and the fostered and unfostered?

There has to be a way to make that happen. That is what I’m looking at for this foster care series. The writings I aim to publish will take a variety of forms, including creative nonfiction, hybrid writing, poetry, fiction, visual and text-based. More importantly, they will come from voices which are undeniably unafraid to speak. If language can do that, I think we can get closer to reinventing our experiences; we’re not so different or alone at the end of the day. Send your writings on foster care to sylvia@entropymag.org. And keep speaking.