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Convocation

Mark Osteen

On Tuesday, February 6, 2018, I sat beside the dirty window in room 435 at Good Shepherd Hospital, where my twenty-eight-year-old autistic son Cameron had been staying since Saturday. There was not much to see from my fourth-floor aerie: a parking lot, a few undistinguished trees, droning traffic passing in the distance. Wearing a yellow hospital gown, I typed on my laptop with surgical gloves over my fingers. Cam lay in bed, listening to one of his favorite CDs, *The Eagles' Greatest Hits*. While he took it easy, I recalled how we had returned to the kingdom of illness.

Lyin' Eyes

Eagles' eyes have a million light-sensitive cells per square millimeters of retina, five times more than humans. While humans see just three basic colors, eagles see five. (H, 2017)

The previous Friday, Cam was scheduled to travel from Hagerstown, MD, where he lives with three

other autistic guys, to Baltimore for an appointment with an otolaryngologist at a nationally known hospital. Ear infections had become a chronic problem for our son: this would be the third visit to this specialist alone. Cam would then spend the weekend with me and my wife Leslie. That morning we got a call from the lead staff person at Cam's residence, informing us that a large bump had grown on the right side of Cam's face, just below his mouth. Should they come to Baltimore or take him to a doctor in Hagerstown?

"Bring him here," I told her. He already had a doctor's appointment, so I figured we could get the bump and ears examined in a single visit.

We met Cam and his aide at the hospital and waited 45 minutes for the doctor, so I had plenty of time to look at my son's face. The lump resembled a boil, but lacked a clear white center. An infected bug bite, maybe? The spot didn't look terrible—a little red, with swelling extending about an inch around the center. Cam was subdued, smiling at me, but not launching into his typical hooting and clapping. There was no point in asking him how he felt: he barely speaks and answers questions only with "yes" or "no, okay," and only when he can muster the focus to pay close attention.

Our history of waiting room meltdowns prompted me to keep him busy, so we ran through our greatest hits. "If You're Happy and You Know It" and "This Old Man" gave way to the Famous Hands Game (straight handshake, soul shake, clasp, touch thumbs; repeat until bored). At length, we were ushered into the exam room,

where a friendly nurse took Cam's temperature. He had no fever.

A few minutes later, the doctor strode in, shook my hand limply, and inspected Cam's ears. This was our third visit, but chilly Dr. Charles barely acknowledged that he'd seen us before. I told him that an ENT in Hagerstown had detected pseudomonas bacteria and prescribed Ciprodex ear drops. Dr. Charles noted that Cam's right ear showed infection. He wanted to add an oral antibiotic, but a suitable one was "contraindicated" because our son takes a low daily dose of Thorazine. The other option was penicillin, but Cam was allergic to that. There was nothing further to do pharmaceutically.

I asked him to look at the facial sore. He took a cursory glance. "It looks like a big pimple." Shrug. We were free to go.

Les met us at home. She was horrified by Cameron's facial swelling, but I reassured her that Dr. Charles hadn't seemed concerned. My thought: she's overreacting, as usual.

Les told Cam that she'd stay with him while I went to a meeting at work.

"By yourself?" he asked. Such utterances—appropriate to the situation and not a memorized script—are so rare that they always trigger questions. Did he mean, "Do you think you can handle me by yourself?" He often confuses pronouns, so more likely it was, "I'll be by myself?" These shards of spoken language emerge unexpectedly, like buried potsherds unearthed by a flood. The phrase—a lengthy one for him—meant he was worried.

As the day passed, the bump grew and Cam's energy dwindled. He refused lunch and an afternoon snack. The swelling increased. Les and I argued about whether he should go to the doctor—with me, as usual, downplaying the problem.

Nevertheless, I googled “facial swelling”; images appeared of something called cellulitis. They looked disturbingly like Cam's face: redness and swelling surrounding a central site of infection. The web sources said cellulitis, usually a streptococcus or staphylococcus infection, was potentially serious. These patients might even be infected with the dreaded MRSA, the methicillin-resistant *Staphylococcus aureus* bacterium that runs rampant in hospitals and institutions. This “superbug” can kill you.

As I scanned the photos, my gut swirled. We needed to get him to a doctor right now! But it was 8:00 p.m. on a Friday evening. I quailed at the thought of the ER. Then Leslie remembered that a new Express Care facility had just opened right down the street.

After forty-five minutes of waiting—during which Cam barely moved and never vocalized, which meant he felt lousy—a chunky, fiftyish doctor with a slight Caribbean accent briefly examined him. He diagnosed a boil which, although not centralized enough to lance, still needed to be treated. He scribbled a prescription for oral Bactrim and sent us on our way. Les and I heaved sighs of relief.

Prescription filled; problem pre-empted. We could relax.

If only.

Heartache Tonight

Many eagle species lay just two eggs and the older, larger chick sometimes kills its younger sibling once it has hatched. The parents take no action to stop the killing. (H, 2017)

The next morning, the sore was worse. Cam's lips had swelled up, the whole right side of his face was puffy, and the central portion of the wound appeared painful and angry. All morning we hoped the antibiotics would take effect, but by noon he hadn't improved. Les's mother called, and when my wife described the sore, she advised us to get to the hospital right away, stressing that we should err on the side of caution. She had managed a physician's office for a decade, so Les trusted her expertise. I scoffed.

"Your mom doesn't know anything about medicine! You two are getting hysterical. Let's give it a few more hours and see if the antibiotics start to work," I said, hiding my own mounting dread.

"That swelling scares me. It looks like MRSA."

"Oh, I doubt it. Do you even know what MRSA looks like? I mean, the ENT didn't think it was anything to worry about."

"If this is MRSA and we let it go, we'll never forgive ourselves."

I rolled my eyes again, but I didn't really feel scornful. I wanted desperately to deny the seriousness of this infection. We'd been through similar predicaments so many times that I knew what would be in store: throbbing anxiety while we

waited for a diagnosis, then a hum of mortal fear providing the backing track for hours and hours of boredom spent in a chilly, uncomfortable hospital room—endless days and sleepless nights. I couldn't face the prospect.

Then I thought of those photos, especially the captions warning that MRSA infections could lead to sepsis and death.

My face flushed. Les was right: Cam had to go to the ER. She called Good Shepherd, located ten minutes away, told the attendant that our son might have contracted a MRSA infection, that he was autistic and had a hard time waiting. Could they accommodate us?

“Bring him in immediately,” she said.

Cam didn't want to leave.

“Hey, bud. You're sick. Your face is all puffy and you're hot, so we need to go to the hospital and see what's wrong,” I said, trying my best to sound unconcerned.

Nope. He wasn't budging. Despite Cam's intellectual impairment, we try to respect his choices; he is an adult, after all. But this was different: his choice to stay in bed was dangerous. Ten minutes of coaxing and cajoling ensued, but our wan, lethargic son still refused to move. Finally, Les and I each grabbed an arm and started to pull him up. Maybe our desperation convinced him; he rose and walked to the door.

A half-hour later, we were ushered to a cubicle in the emergency room.

As we bided time, a female patient complained about her legs. “I don't have my meds,” she wailed,

“and the pain is so bad.” She whimpered loudly. For the next couple of hours, she moaned and berated her toddler daughter, until she was discharged—without pills.

The resident, a youthful man named J. Gupta, confirmed that Cam had cellulitis, “a potentially serious, even lethal infection,” and started him on intravenous antibiotics.

That’s when I got really scared.

I remembered when twelve-year-old Cam had jammed rice and paper up his nose and had to be sedated so the objects could be removed (the surgeon also found sundry items in his ears). I recalled the numerous visits to emergency rooms after Cam’s seizures, beginning when he was sixteen. These incidents seemed to blend together, but they never became routine: each episode introduced a new reason for dread.

After several hours, I left to get us dinner. When I returned, Cam was resting in room 435.

New Kid in Town

Eagles have a specialized mechanism in their feet that allows them to lock in position so they can sleep while sitting on a branch. (CCB, 2020)

For the next day and a half, tedium alternated with terror. How serious was this illness? Was it MRSA? Our son looked terrible, his slim, handsome face ashen and bloated. The nurses took a culture and changed his IVs (loaded with the antibiotics clindamycin and vancomycin) as we sat

with him. He was too sick to do anything but lie there—in some ways a blessing, because otherwise he'd clap, howl “hoo,” try to rise, and noisily masturbate. Several hours passed, and the time began to weigh heavily—until I considered where we were and what this meant. Fear elbowed out the ennui. It wasn't only the sore and swelling that frightened me; I was also wary of the antibiotics.

In 2011, a round of clindamycin Cam took for strep throat wiped out his gut flora and brought on a *Clostridium difficile* infection, which caused a high fever and horrendous diarrhea, and led to three days in the hospital. Cam expressed his opinion about the experience early in day three after he'd leapt from his bed, only to be forced to lie back down.

“It's a bullshit!” he'd yelled.

This time he didn't even have the energy to shout.

Saturday night, Les dozed in a recliner in the room; at 10:30 I went home to sleep and returned early the next morning. Cam's face, though still grossly swollen, looked a little less grotesque. Oddly, his left side looked completely normal, but on the right side his lips had lifted from his teeth and his cheeks were inflated; the swelling had even reached his neck. The sight brought to mind a classic *Star Trek* episode featuring an alien race whose faces are black on one side and white on the other. Did Cam feel like an alien? Probably. But he'd had far more experience with hospitals than most people his age, so he knew what to expect. We explained why he had tubes running into his arms and why his face

was swollen. He seemed to understand, then turned over in bed and tried to sleep.

The next morning, the resident, a tall South Asian man, told us that Cam was in sepsis, which meant that the infection had entered his bloodstream and become systemic. It's what we used to call "blood poisoning." Hearing this, my face flushed. My heart felt like it was going to pound through my chest. I looked at Les; she'd gone white.

The resident must have noticed our panic. He reassured us, "But the antibiotics are already working, which means that he's very likely to come out of this okay."

For several hours we anxiously monitored our son's breathing.

Later that day, Linda, who called herself the "nurse refresher," gave Cam a sponge bath and chatted with me about music. It was Super Bowl Sunday, so the conversation drifted to football. She didn't know much about the sport, but was excited that the Eagles were playing. For some reason, I thought she was referring to the halftime show.

"Oh, I didn't know they were performing. People think they're cheesy, but they're one of Cam's favorite bands." I recalled the first rock concert I ever attended. After driving 160 miles to see Jethro Tull, my friends and I impatiently sat through the opening act, an unknown band with a drummer who sang their first number, "Witchy Woman." "These guys aren't bad," I'd thought, "but they're too countrified. They should play more hard rock."

She gave me a blank look.

“I should have recognized the musicians,” I explained. “Because The Eagles were a supergroup. The members had played in top bands like Poco and the Flying Burrito Bros.” Her face told me I was lapsing into lecture mode, so I switched to Cam’s love for music. He had carried his adoration of Raffi into his teens before switching to classic rock. The Beach Boys, Mellencamp, The Beatles, and Foreigner were favorites. And, of course, The Eagles.

Only later did I realize she’d been talking about the football team. No wonder she seemed puzzled.

But the conversation inspired me to find out more about eagles—the birds, not the band—so I did a Google search. Did you know that a gathering of eagles is called a convocation? (“Your Dictionary, n.d.”). That the golden eagle can fly at a speed of up to 200 mph, which makes it the second fastest bird in the world (after the peregrine falcon)? (H., 2017) I didn’t. For some reason I found these factoids comforting.

After dinner, we watched the big game on the tiny TV wedged onto a shelf near the ceiling in a corner of the room. Or rather, Les and I watched the game while Cam alternately dozed and re-viewed Imagine Dragons’ *Smoke and Mirrors* video on his mini DVD player. I shouted with glee when the Philadelphia Eagles dispatched the New England Patriots in the final minute. Unfortunately, the (other) Eagles did not perform at halftime (it was only Justin Timberlake). Cam took it all in stoically, though he clapped with us as we celebrated.

That day I read most of Rachel Hadas's *Strange Relation* (2011), a memoir about her husband's dementia, finding it therapeutic as well as wise. I ummed in agreement at this passage: "The kingdom of illness gives some gifts; it bestows an alarming clarity on the way those inside it view those outside" (p. 33). Of course, autism is not an illness, but a lifelong condition. Nevertheless, her words reminded me that we'd been living in this kingdom for twenty-seven years. At certain moments, such as the present one, everything beyond its borders, even the Super Bowl, feels trivial.

Even so, the weekend's confluence of events seemed meaningful. Hadas recognizes this too, quoting a line from Wallace Stevens's *Notes Toward a Supreme Fiction*, which reads, "Life's nonsense pierces us with strange relation" (as cited in Hadas, 2011, p. 46): A relation between a rock group and a football team, between a dangerous infection and a hype-laden sporting event, or between awe-inspiring avian raptors and an autistic man and his parents. Strange, but somehow fitting.

Best of My Love

In most eagle species, females are larger and stronger than males. (H, 2017)

That night snow and ice fell, so the next morning I couldn't get back to the hospital until 10:30. I hustled through the corridors, frantic about Cam, worried about Les's fatigue, only to find room 435 empty. My mouth flew open and my gut churned.

Oh my God! Did something terrible happen?
Calm down, I told myself; Les would have called.

Moments later my wife and son returned from the immunology department with good news: Cam was no longer allergic to penicillin. These were welcome tidings, because they brought back into play a whole class of less risky antibiotics. Even better news: the swelling had gone down and Cam's color and mood had improved. By noon, he even felt well enough to play the "ha ha" game with me.

Cam: Hahahahaha!

Dad: Haha haha haha!

Cam: Ha ha ha!

Dad: Hoo hoo hooo hoo!

Cam: (Bemused look.)

On Sunday and Monday, a stream of medics passed through the room. We met Dr. Prentice, an African American infectious-disease resident who looked like a college student; we were introduced to the affable, brisk Dr. DeLand, a white woman in her late forties; we shook hands with Dr. Margolin, a chubby surgeon with reddish blond hair and a confident, congenial manner. He announced that he would lance the abscess on Cam's face. He added, to our dismay, that MRSA "presents like this."

Cam had been as brave as an infantry soldier and my wife had been sleeping (badly) in the chair and tending to his every need. I spelled her each day for a few hours at a time, feeling helpless and

inadequate. But as Cam's well-being improved, the stay grew more fraught, because he now had to be entertained. Several times he tried to get out of bed (hollering "potty") without noticing the IV lines attached to his arm. Each time we had to stop him and make our careful way to the toilet, taking tiny steps as we rolled the IV cart beside our son.

On Monday, he rewatched (for the thousandth time) his collection of kids' videos and his Train and Imagine Dragons concert videos. This time, I listened to Imagine Dragons' lyrics. These lines from "Shots" resonated: "Am I out of luck? / Am I waiting to break, / When I keep saying that I'm looking for a way to escape?" Cam couldn't escape yet, so he reviewed his video of the gray, pudgy Eagles performing live. Then he let *Aladdin* play from beginning to end. If only we had that magic lamp.

It struck me then that Cam had spent a good portion of his life as a patient. Glancing at him calmly watching his video, I grasped the word's meaning anew: being a patient means that you are not an agent, that others care for you and act on your behalf. My son, who seemed so helpless and needed so much support, was exercising his agency by remaining patient. He was demonstrating how to handle boredom, pain, and fear.

On Monday, I began reading a biography of the eighteenth-century literary forger and prodigy Thomas Chatterton, a fatherless boy who died at seventeen. Despite its many fascinations, this book troubled me. Cam was older than Chatterton was when he died. Youth offers no protection against

mortality. This book and Hadas's will be forever linked in my mind with this Super Bowl weekend. Strange relations.

As Cam got into the chair that would wheel him to the OR and get the abscess lanced, I started to tear up. It did little good to tell myself that there was no reason to get weepy, that this was a minor operation, that the worst had already passed: I knew that my son couldn't speak or care for himself and that, despite his strong heart and spirit, he was extremely vulnerable. As he sat there gazing up at me, I read his eyes: Mom and Dad are here. I'm safe.

I wished I had his faith.

Already Gone

The Navajos believe that eagles are charged with carrying prayers from this world to the heavens. (Morales, 2015)

Dr. Margolin lanced the spot expertly. As usual, it took Cam a long time to wake up from the anesthetic. The anesthesiologist checked on him several times and a nurse named Beverly tried to rouse him. Finally, after almost three hours of twilight sleep, he opened one eye and announced, "Potty!" He had to get up NOW. My son is around my size, so I struggled to hold him down as he writhed and yelled and Beverly tried to remove the IVs.

She shouted, "Could we get some help here?!" Within seconds we were surrounded by nurses and doctors. It was a convocation of medics, a huddle of scrubs! Breathing hard, I helped them calm

Cam and unplug him from the machines, then held his arm as he woozily walked to the bathroom.

Now the most vexing problem was keeping the dressing on the wound. Cam has always hated having anything on his skin. For years he wouldn't wear clothes at home. In 2009 he accidentally put his arm through our picture window and had to get stitches. After an entire morning in the ER, we went home; within five minutes he removed the stitches, forcing us to return to the hospital, where the doctor reluctantly discharged him without stitches. The gash eventually healed on its own. As expected, moments after returning to room 435, Cam yanked off the bandage and packing on his face. The nurse applied a new one; he pulled it off. And again. When I started this essay, Cam was wearing hospital mittens to prevent him from scratching the wound. He couldn't eat or drink while wearing them, so he ripped them off several times to grab a cookie and spoon up some apple sauce.

He was picking at the wound as I typed the first draft of this essay.

Two pieces of news highlighted our day. First, Cam did not have *C. diff*: vancomycin is a preferred treatment for it, and he had been taking that since we arrived. Second, his facial infection was MRSA. Our son contracted a superbug just in time for Super Bowl Sunday. Hence the mask and surgical gowns, which we were told to wear every minute we were in his room. The garb made me feel like some weird blend of baseball catcher and bio-weapons soldier. Strange relations again.

The news about MRSA terrified us, but we took comfort in knowing that the antibiotics were working. Cam's face looked more normal again, aside from the bandages (and the four-day whiskers). Even better, Dr. Gupta dropped by to tell us that our son would likely be discharged the next day.

Tequila Sunrise

Eagles are smart birds. For example, in Greece, golden eagles eat turtles, dropping them from great heights onto rocks to break open their armored carapaces. (H, 2017)

Cam was released from the hospital on Wednesday afternoon. At 1:30 p.m. he'd fallen asleep, so we had to work hard to get him into the wheelchair and out the door. He was still sleeping at 5 p.m.—not surprising, since he'd spent much of the previous night pulling at the dressing. The nurse had insisted on replacing it each time he removed it; two minutes later, he would tear it off again. This went on, Les told me, for several hours. Nobody got much sleep. When I arrived that morning, he had no bandage on his face.

I gritted my teeth when I considered that picking at a sore was probably how Cam got the staph infection in the first place. How do you keep a grown man from hurting himself? A wave of anger washed over me—not at him but at the aides who had neglected his hygiene. We were told to apply warm compresses four times per day so it didn't

heal too rapidly and fail to “allow drainage.” But the absence of a bandage exposed the sore in its true hideousness. My son had a hole in his face! How could I not worry?

Another splinter of pain poked through the relief: Cam had had a runny bowel movement that morning. Was it *C. diff*? Dr. Gupta explained that all antibiotics can cause diarrhea. Unless Cam defecated four or five times and spiked a fever, we needed only to watch him closely. Believe me, we did.

Despite our fears and our son’s suffering, this was one of the most positive experiences we’d had in two decades of dealing with Cam’s medical professionals. They’d cured his illness, quelled our fears, and cared for him respectfully. But something had to go wrong. Fortunately, it was minor this time: he was in the hospital records as “Carmeron.” Les corrected it at the allergy test, but his discharge papers retained the misspelling.

“Discharge”: the word conjured up images of yucky bodily fluids prepared to contaminate any careless handlers of those trash cans with the frightening yellow labels. It was as if the hospital ingested patients and spit them out, or as if Cam had been in the army and was now returning to civilian life. His discharge was honorable; in fact, he deserved a Purple Heart. Perhaps, then, his new name was appropriate, for this experience had changed us all.

Make no mistake: hospital care is institutional care. Patients get meals (most of which Cam wouldn’t eat) at set times, and good luck trying to get a Coke (one of Cam’s cravings) on a short-stay

floor. There was never more than a single good chair in the room, which is why I had to drive home to sleep. More important, we'd been shown again (as if we needed more proof) that the neurotypical realm—even the domain of healthcare, which is designed to be humane—struggles to accommodate the Camerons of the world.

And yet his presence created ripples; because he needed care, he invoked compassion. He had called forth a convocation of professionals and had enabled them to be heroes. He had brought us all together.

The Long Run

Bald eagles tend to pair up for life and share parental duties. The male and the female take turns incubating the eggs, and they both feed their young.
(CCB, 2020)

On Friday, Cam returned to Hagerstown. His primary care physician assured us that the sore was healing well and that the “vanc” would prevent *C. diff* from taking hold. Not only was she pleasant and competent, but unlike Dr. Charles, she took time to chat with us about Cam’s health, personality, needs—his life. She treated him like a human being.

We returned to the quotidian crawl with renewed admiration for our son, who had coped with this terrifying experience without complaining or causing trouble. Yet a sense of unease lingered. The MRSA could have killed him. What if he hadn’t been home with us? Would his aides

have acted quickly enough? He has no way to say what hurts and how much. I couldn't bear to think of what might have happened then.

In fact, all of Cam's recent medical problems—the *C. diff* of 2011, an eating disorder in 2014, his chronic ear infections and the MRSA attack—are indirect consequences of his autism and intellectual disability. Neurodiversity advocates argue that autism is merely a different way of being human, no better or worse than the neurotypical way. In many respects I agree with this stance, and I applaud how it helps to preempt prejudice. I also know that Cam's autism is more than a difference. Even if you grant, as I do, that a disability always involves a relationship between a person and the environment, this experience reminded us that no environment, not even a hospital, can fully accommodate Cameron. Our world is not set up for people like him and never will be.

And we only seemed to have dodged a bullet, for the slug damaged Cam's face (which would bear a noticeable scar) and overall health. It also hammered a big dent in our sense of security. His well-being, we learned once again, depends on the alertness and diligence of people who don't know him, as well as the love and devotion of those who do. Hadas (2011) puts it beautifully in her poem "Bath":

Now that I am far away I see
clearly that your illness is a bath
in which you soak, then presently climb
out.

In vain: this bath goes everywhere with
you ... (p. 81)

Cam carries a hospital wherever he goes: he takes a packet of pills daily to dispel his anxiety and aggression, prevent seizures, dampen his acid reflux, heighten his mood and boost his appetite. He requires someone to help him bathe and brush his teeth, fix his meals, give him his medications, drive him where he needs to go. In other words, Cam is in some sense always a patient, and the hospital was, for him, merely an extension of his daily life. Like a guest at the Hotel California, he can check out, but he can never really leave.

The books I read during his stay were valuable, but the most significant reading I did was in the Book of Cam. That text provided helpful instructions about how to handle discomfort and dread and revealed again that music gives solace for the soul. I realized once more that although our son depends upon us, we also look to him for a different kind of strength and for alternative types of knowledge. We are interdependent. Before long, I knew, we would re-enter the kingdom of illness, counting on love to sustain us. That love would have to be a strong one; it would need to be as super as he is.

*Some eagles use columns of hot rising
air to enable them to soar for long
hours without a single wing beat.*
(H, 2017)

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Mark Osteen is Professor of English at Loyola University Maryland and the author of *One of Us: A Family's Life with Autism* (University of Missouri Press, 2010). For more information, see <http://www.markosteen.com>. Email: mosteen@loyola.edu