Ars Medica

Volume 18
Issue 1
2024

My Injured Brain

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For years, it’s been common for me to run errands, quite literally. Almost weekly, I tuck cash or a credit card into a sock top, lace up my running shoes, and jog to a coffee shop or store. Once there, I pick up nothing more than I can consume on site or carry home on my own two feet.

This was my plan on October 22, 2009, during a visit to my elderly parents in my former hometown, a suburb of Columbus, Ohio. Not long before my visit, a high school friend’s mother was laid to rest in a local cemetery, and because my friend now lived more than 500 miles away from this cemetery, I wanted to leave some flowers on the grave in her stead. On the morning of the 22nd, I ran 2.1 miles to a local supermarket. The plan was to buy some flowers and walk them to the cemetery, just under two miles from the store.

I remember reaching for a pot of mums. They might have been yellow, or they might have been orange. Then the flowers, the store, and any sense of myself ceased to exist. I can’t say these things vanished, because that would suggest that I understood something had happened or changed. The next thing I saw was my brothers, smiling at me from either side of the hospital bed I’d been laid out on. Behind them, an Ohio State football game played on the wall-mounted TV.

What are they doing here? was my first thought, as happy as I was to see my brothers. Grant lives in North Carolina and Neil in Virginia, and with their busy lives, they couldn't have just swung up to Ohio in a flash. Soon after, my beloved husband entered the room, after having traveled 700-plus miles from our home in Boston. A dear cousin also appeared, having made her way to the hospital from West Virginia, where she held a more than full-time job. Seeing her brought me to (good) tears.

As it turned out, my brothers, husband, and cousin had had plenty of time to travel to Ohio. Not long after emerging into this new reality, I learned that I'd reached for those mums two days earlier. Sometime before or after getting them into my hands, I'd fainted for the first time in my life, fracturing my skull on the floor of that supermarket. At some point between my fall and my arrival at a local hospital's trauma unit, a kind soul fished my cell phone out of the backpack I'd been carrying, found a number in my contacts labeled *Mom and Dad*, and started the chain of calls that would bring many loved ones to my bedside.

A central concern: my cognitive functioning. My brain.

I remember my mother sitting in a corner of my hospital room, smiling when I caught her eye. Only in retrospect did I see that we'd become connected in a new way, a way that neither of us would have wanted. Though I didn't know it at the time, her brain was in trouble too.

* * *

I'd traveled to Ohio to drive my parents to a family gathering in Pennsylvania. My father's vision was declining, making him more and more wary of getting behind the wheel, and my mother had always avoided highway driving.

But Dad didn't want her driving at all. A year or so before, he took me aside and told me he'd started insisting on driving Mom to her regular destinations, mainly the local library. Her judgment wasn't what it used to be, he said, and he feared she'd get in an accident. Though this concern came from a self-described "professional worrier," I respected his decision.

What he said next was far more difficult to hear: "I feel like I'm living with a stranger." The woman he'd fallen in love with seemed to be vanishing, he said, becoming more and more detached, mentally and emotionally. Sometimes, he said, he'd find her just sitting on the couch or at the kitchen table, staring blankly ahead.

I don't remember what I said in response, but I'm sure it wasn't helpful. How could it have been?

What I didn't say: *I don't see what you're seeing, Dad.*

Though my mother had slowed down physically, she seemed as socially active as ever, keeping in touch with her many friends and staying on top of multiple pursuits: art class, family-history research, and book group, to name just a few activities. Also, I didn't sense that our relationship had changed in any way, nor had I noticed any changes in her behavior.

Looking back, I think, *Maybe I only saw what I wanted to see.*

* * *

Those first two days in the hospital—before I woke to the sight of my brothers—were a blank for me, and my husband tells me that I seemed to be in a deep sleep. When I came to, I felt no pain, an absence that was to continue, even though the back of my skull had been split open and then fastened closed with staples. No doubt strong painkillers were a factor, but, especially in those early days, I also sensed a certain separation from my physical self, as if I were floating along in a sort of twilight state. During those rare times I wasn't sleeping, I was somewhat aware of my weight on the bed—and of the comings and goings of hospital staff—yet never fully present in the living world.

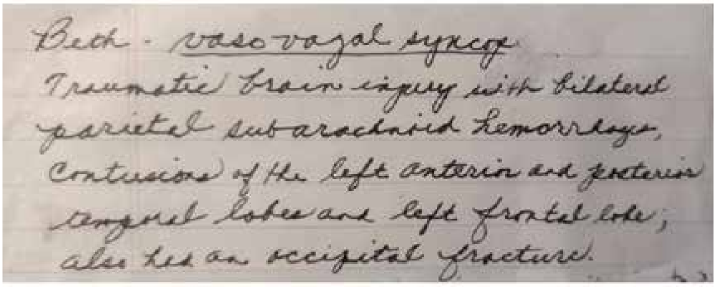
After my transfer to a rehab facility, I began to gain a clearer understanding of my diagnosis—traumatic brain injury (TBI)—and of what it might mean for me, not only as a wife, a daughter, a sister, and a friend, but also as a writer. Not quite a year before, I'd left a publishing job to devote more time to writing fiction, allowing me to finish one novel and make good progress on a second. Now, I couldn't even read—at least not the way I used to. I remember picking up a *New Yorker* someone had left at my bedside and trying to take in the opening lines of an article.

There's a word, and there's a word, and there's a word…

If someone had asked me to define one or more of them, I probably wouldn't have been at a complete loss. Still, I could only take the words in separately, as if stringing beads, and I was unable to make sense of whole sentences, much less connect them to understand the writer's larger point.

If I couldn't make meaning from someone else's words, how could I possibly assemble my own, not only logically but also in a way that might interest me, or anyone else? As for making any further progress on that half-finished novel, I tried to push that notion out of my mind, never fully succeeding.

My TBI followed vasovagal syncope (VVS), a sudden drop in heart rate and blood pressure that, in my case, led to fainting. Although my doctors presented various theories about why I'd experienced VVS for the first time in my life, nothing was certain, and no explanation ever felt satisfactory. One theory was dehydration, but as a nearly lifelong runner, I'd always been careful to drink enough water, especially before long runs and during road races. What was clear were the details of my TBI, which my mother—long the family documentarian—recorded in her elegant cursive on a sheet of notepaper, which I discovered tucked into her address book after she died.



Beth - vaso vagal syncope
Traumatic brain injury with bilateral
parietal subarachnoid hemorrhages,
Contusions of the left anterior and posterior
temporal lobes and left frontal lobe;
also had an occipital fracture.

Note: My mother's notes about my brain injury, indicating hemorrhages, contusions of the left anterior and posterior temporal lobes and left frontal lobe, and an occipital fracture.

Even before my accident, I understood that injuries to the left side of the brain might be especially bad news for someone like me. Specifically, they can make it difficult to express oneself in spoken or written language, and to understand language of both kinds. My experience with *The New Yorker* suggested that my future as a reader wasn't promising. As for my future as a writer, that wasn't put to the test during my days in inpatient rehab, and I dreaded when it would be. The only cognitive tests I recall were being asked to repeat brief series of words forward and backward, and to draw a clock face with hands pointing to a particular time. I don't remember how I did on these tests, but if my performance was lacking, no one let on.

* * *

A few years after my TBI, my mother underwent the same types of tests from her GP. She'd done so at my father's urging, and she seemed untroubled that he'd found such tests necessary, as if she was only humoring him.

She appeared to accept the result—a diagnosis of mild cognitive impairment—with the same equanimity, and she continued with life as she'd known it.

For my part, I tried to square this diagnosis with my latest impressions of my mother, who seemed as active and socially engaged as ever. But perhaps her afternoon naps, an old habit of hers, were longer than I remembered? And maybe she was having a bit more trouble following the plots of the movies we watched together?

I wanted to face facts and not deny any clear signs of decline. Still, I thought, *at 83, she's still going strong. She might go on strong for years.*

Perhaps I wanted to believe this for my sake as much as hers. Maybe I, too, could live to be a bright and active eighty-something, if only out of sheer force of will. As if I'd never injured my brain.

* * *

Within a few weeks of my TBI, two old, interrelated drives resurfaced in me and helped keep me going, both in the rehab facility and beyond it: the desire to run, something I've done almost every day as an adult, and pure stubbornness. I wanted to get back on my feet and get moving, and the turtle's-pace stride on a treadmill that was part of my physical therapy just wasn't cutting it. Feeling especially emboldened one afternoon, I snuck out to the parking lot of the rehab facility and jogged around it a couple of times, worried I'd be found out and hauled back into the building and also elated to be breaking a sweat on a crisp fall day.

After I returned to Boston, my desire to run stayed with me. Although, paradoxically, I spent most of those early months sleeping, I was eager to go out for short runs every day. What I couldn't do was read anything lengthy or complex. I also couldn't write.

However, within hours of returning home, I did read the opening lines of a pamphlet that my husband had been given at the hospital or rehab facility, a pamphlet that, in retrospect, I think of as a coiled snake. I don't remember how I came across it, but I'll never forget its effect on me.

> *Accept that your loved one will never be the same, that they will be diminished …*

I'm sure these aren't the exact words, but they're the gist of what I read. I remember the jolt they delivered. And I remember looking between them and the nearest window, three stories above the ground, and sensing an invitation: *Jump*. Although I knew I'd never accept that invitation, the pamphlet's message lent a cool logic to the notion of doing so.

Then my stubbornness kicked in, and my anger. I marched the pamphlet to the trash bin and tossed it, and I remember thinking this: *If enough of my old brain power remained for such doomsaying to equally horrify me and piss me off, not all could be lost.*

And it wasn't. In the weeks and months that followed, I took a measure of relief from each small success I logged during outpatient rehab in Boston, whether that was making blueberry muffins from a boxed mix in occupational therapy, or finding my way to a list of destinations at a local train station. All along, the running (and stubbornness) felt inseparable from the healing of my brain and body, and from my return to reading and writing. At a distance of more than ten years, I can't recall the experience of reading a book for the first time in months. Nor can I remember what it was like to reopen the computer file of my novel-in-progress and, eventually, find my way back into a story that I thought I might have been locked out of, for good. All I can say is that somehow, I did, and eventually, it became my first published novel.

I can also say that there was nothing magical or especially remarkable about my return to that novel. Looking back, it seems that at some point I just reacquainted myself with that close cousin of stubbornness: routine—in particular, my old routine of sitting myself down in front of my computer and trying to put down words, a habit enforced by my inner taskmaster, and by the certainty that, for me, there's no such thing as creative inspiration. The only way I can start, and hopefully finish, a piece of writing is to put in plenty of time trying—often, unproductively. But every now and then, time itself seems to vanish as I immerse myself in the world of a novel or story. Sometime in 2010, I was able to achieve that state once again.

In describing my return to writing, I'm not aiming to tell a tale of redemption or of persistence paying off. And the notion of trying to extract, and share, any lessons from my experience feels both simplistic and irresponsible—an attempt to impose order and meaning on something (the state of my post-TBI brain and my powers of cognition) that presents an ongoing and evolving mystery. Yes, I keep writing. Yes, I have hope for my future as a writer, and as a person with a purpose and interests and many beloved people in my life. At the same time, I realize that hope is a fragile and perishable thing, and for me, for now, its major opponent is fear. Fear of my mother's fate becoming my own.

* * *

A couple of years after her diagnosis of mild cognitive impairment, my mother underwent surgery to clear a mostly blocked carotid artery. The procedure failed and had to be repeated, and she developed serious post-surgical infections. Far worse, in my view, was the toll that the surgery had taken on her mind. When she wasn't sleeping, which was most of each day, she kept to herself, not wanting to see friends or extended family or even take their calls. And she repeated questions, something she'd never done before. In short, she'd descended into full-blown dementia, which was eventually diagnosed as vascular in nature.

I believed that I'd failed my father in not seeing—or refusing to see—what might very well have been the earliest signs of this descent, something that had been so clear to him. And I understood that when he first told me he was losing her, he was already deep into a grieving process that, for me, was only beginning.

Although my mother's surgical infections eventually healed, her decline continued, and she died 16 months later, four months after my father, whose mind was sharp until the end. Is it selfish that I've found relief in that sharpness—a hope that I might have inherited its lastingness—even though it became a curse to my father, as he witnessed my mother's descent?

* * *

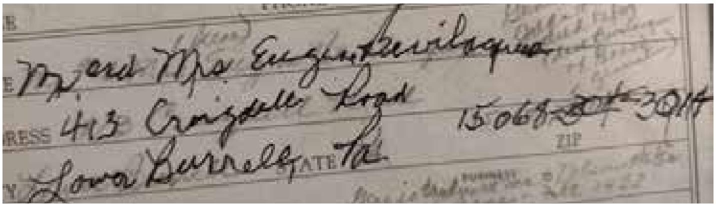
Even before my TBI, even before the loss of my mother to dementia, I feared the failure of my brain more than anything else that might befall me. Since I've become aware of the association between a major TBI and dementia, that fear has intensified and grown more present—though physical activity seems to be a mitigating factor, according to a recently published study (Raj, Kaprio, Jousilahti, Korja & Siironen, 2022). When I enter what seems like a longer-than-usual blank state while writing or struggle more than I remember to enter the world of a story, I often wonder whether my cognitive abilities have begun a new, more lasting descent and, if so, how far and how fast they might fall.

Still, I've tried not to dwell on the details of my TBI, though I sometimes revisit the address book where my mother recorded them. Among all the possessions of hers that I've held on to, it may be the one that I value most, because it served as an impromptu journal for her, a record of her ongoing interest in the lives of friends and family, which she maintained until she couldn't.

Throughout its worn pages, she recorded—mostly on sticky notes—various updates and also quotidian information preserved (presumably) for future reference:

> *Charles ____ had a stroke last August.*
> *2006: Kelly is back in Syracuse. Has job as PR manager…*
> *Steeler and OSU scarf lady, ________. Cost per scarf $20.00*

The address book also holds evidence of her decline. Paging through it after her death, I discovered what must have been some of the final jottings of a woman who for years had taken so much care with the form and substance of her writing. In them, I saw the new unsteadiness of her hand, and mind, as she struggled to maintain her cursive's elegance.



Note: An update to an old address in my mother's address book, made after she developed dementia.

I'm haunted more, though, by how my mother's love of books outlasted her ability to read. My most abiding memory of her, from better times, is of her stretched out on the side of the couch lit by the reading lamp, engrossed in one of the thousands of books she'd read over her lifetime. If ever I had cause to interrupt her, she'd look up over the rims of her reading glasses, not unhappy to see me, but clearly ready to return to her book as soon as she could.

Sometime before her failed carotid-artery surgery, she borrowed *The Warmth of Other Suns* (2021) from the library that was a second home to her. During one of my phone calls to her—early in her first postoperative hospitalization—she asked me to bring her this book and her reading glasses. After I delivered them, they were to travel with her to a rehab facility and then back home and then back to the hospital and then back to rehab. As I recall, the book and her glasses remained mostly at her bedside, ignored. But every now and then I'd find her with the book, always open to the middle, on her lap. Although it appeared that she'd made no progress through it over the course of my visits, she seemed to have found comfort from the physical memory of her old routine, from the weight and feel of a book. At one point, I was surprised to hear her say how much she loved *The Warmth of Other Suns*. Even if she never read a single word of it, I believe she was completely sincere. In that praise, I heard and felt her love for all the books she'd ever enjoyed, and for reading itself.

These memories of my mother's decline haunt me because they remind me of everything she was in her best days, and of everything she lost. I can't deny that the memories also intensify my fear about the fate of my own brain and cognitive abilities. A family history of dementia, coupled with the TBI, almost certainly puts me at a heightened risk of experiencing the sort of decline that my mother did. So every day, I try as best I can to train my thoughts toward the here and now, telling myself that for as long as I can, I'll continue to run and read and write. And without basis or reason, I sense that my stubbornness will outlast all of these drives and abilities, and that I'll continue to feel—or remember—myself striving and striving and striving for something even if, eventually, I no longer know what that something is.

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