

Hold On

I'd forgotten you exist!"

I don't quite remember my response, although my smile remained frozen. I was attending the fortieth birthday of a colleague from my PhD program at Berkeley and her childhood friend, a neurological nurse practitioner. The nurse's team had overseen part of my husband's care in the ICU. During my three-month hospital vigil I'd returned to Peter's bedside every night once the children were asleep, thanks to a rotation of generous friends. This party was my first social foray out of our house after dark.

"I'd forgotten you exist!"

I turned these words over in my head over the following year of mostly single-parenting, spousal caregiving, intermittent working, and relentless homemaking. I can't fault her honesty. In some moments, I've forgotten that I exist, too.

Just over a year ago our family of five moved back to San Francisco, after five years away in Athens, Paris, DC, and LA. During our travels, I researched and wrote my dissertation (on theories of color) and Peter worked as an IT engineer from the living room of our apartment in each new city. He owns a killer set of headphones.

Our first child, Soren, was a souvenir from an idyllic trip to Tuscany and Rome. We'd been so surprised that I'd taken four pregnancy tests, prompting Peter to question the statistics on false positives. Very low, it seems. Soren was born in San Francisco just before I began researching my dissertation. Lilith, our middle child, was born two and a half years after Soren, in Paris, at the Maternité Mona Lisa. Soren gave his sibling the middle name Delphi in honor of our travels to what was once called "the navel of the world." Our third child, Astrid, was born under a blue moon in Los Angeles, on the last day of August, four days before I started a post-doctoral fellowship. We'd left San Francisco with one small child. Five years later we returned with three.

Such a small thing: we never used the bureau that we'd kept in storage all those years away so we offered it to our new neighbors. On a regular Monday just after work, our neighbor came over. They hefted the bureau and moved towards the door. Peter tripped on a recent repair to the landing. With no railing to catch him, he fell over the stairwell. I heard the loud crack of the bureau smashing to the uneven pavement a story below. I ran to the landing and at first I saw only the shattered bureau. Then I saw Peter sprawled about a foot away, unmoving.

My memory and our children's memories of what happened next are brutal pictures. They reassert themselves daily, whenever a siren sounds, when we drive by the old apartment, when someone around us trips or bleeds. Peter lives each moment with the injuries themselves, but remembers nothing of the accident, the emergency response, his time somewhere between life and death, his craniotomy, the month in intensive care. He remembers nothing from that day. He woke up five weeks later in

a rehabilitation hospital in a beige room papered over with get-wells cards and our children's drawings. Peter and I are bound by this traumatic experience, yet in that instant our lives diverged in ways that we still struggle to reconcile.

Our neighborhood in San Francisco is gritty, loud, and proximate to two freeways. It has one other crowning jewel: San Francisco General Hospital, the city's only Level One trauma center and a microcosm of the city itself. If you've been shot, wrecked, run over, overdosed, or felled in San Francisco, you're taken to the General. As a public hospital, they accept everyone with or without insurance, and they also have a renowned approach to emergency care. The head of neurosurgery at SF General hospital, Dr. Manley, also treated Bob Woodruff, the ABC journalist who sustained a severe traumatic brain injury from a roadside bomb, while reporting from Iraq. He also oversees some of the longest running studies of brain injury today. Remarkably, he answers his own cell phone.

Our friend Elly set up two playlists for Peter's room in the ICU: Peter Heals—Day and Peter Heals—Night, to play. He had no windows by which to distinguish night from day; instead, music and the shift changes divided time. Day was Ryan Adams, Tom Waits, and Billie Holiday; Night was Brian Eno, Andrew Bird, and Zen Magic Garden. One nurse liked the music so much she asked me in earnest to help her track down the musician Peter Heals. We moved the music with Peter to each successive hospital, creating a cocoon in each new space.

Well your old hometown is so far away/But, inside your head there's a record/That's playing, a song called/Hold on, hold on/You really got to hold on/Take my hand, I'm standing right here/And just hold on.

One night in the ICU, Peter was certain that we were back in Paris. Another night when they lowered his sedation he insisted that I was not his wife.

"My wife," Peter rasped, looking around with frantic eyes.

"I am your wife," I said.

"No, you are not," Peter insisted.

"Yes, I am."

"No!"

"What does your wife look like?"

"Like you."

"And what is her name?"

"Jennifer."

"Oh, she looks like me," I answered with false brightness. "My name is also Jennifer. That is because *I* am your wife."

“No, you are not.”

Soren and Lilith are dressed in shiny, elaborate armor and duel with leather swords.

“My name is Inigo Montoya! You killed my father. Prepare to die!” shouts Lilith. We’d watched *The Princess Bride*, which added specificity to their regular duels. At times one is Wesley; at others, the six-fingered man, but one of them is always Inigo Montoya, avenging his father.

“Stop!” cries Astrid. “Stop, saying that! Papa is *not* dead!”

Astrid’s protest stunned me. She’d barely begun to speak at the time of Peter’s accident, and I’ve never been sure how much she understood. Like the rest of us, she was present at the scene. She’d been, however, small enough to accompany me regularly to the hospitals, tucked in a carrier on my back.

Her objection shouldn’t have surprised me. His accident has dominated more than half of her life. There are other signs that she thinks about what happened. She doesn’t have bedwetting nightmares like her siblings, or their daylight flashbacks to the scene. She hasn’t drawn Papa’s bloody face, or commented that cerebral spinal fluid looks a lot like pee. She does scroll through the hospital photographs stored on my phone to watch the video of his first halting steps in relearning how to walk. She recounts the story stripped to its bones. “Papa fall?” She asks. And then together we repeat “Papa fell, but now he is ok.”

Peter is easier with Astrid’s laughter and hugs than with the angry movements of his older children, who miss being tossed into the air with the certainty of being caught, of roughhousing on purpose, and not because their father no longer understands the strength of his damaged hands.

Over dinner one night, Lilith said in their clear, sweet voice:

“Papa, you were a much better dad before your accident.”

While Peter’s intellect has not diminished, his capacity to grasp emotional nuances certainly has. Within the walls of the rehabilitation hospital it was easy to be grateful for how well Peter was doing, how smart and familiar he seemed. When we returned home, however, it became harder to hold on to that gratitude and easier to compare him to his pre-injury self, or to the uninjured fathers around us.

In intensive care, when the nurses lowered his sedation to check his cognitive status, they would place a photograph of the children in front of him. I’d brought a family shot taken in front of a fake volcano from the Pompeii Family Festival at the Los Angeles’s Getty Villa. The children had glued volcanic rock to the frame. Astrid is wrapped to my chest in a blue cloth, Soren, Lilith, and Peter are wearing matching Nordic sweaters; Soren’s head is bowed to hide his face and Lilith is trying to escape stage left. Only Peter and I are smiling at the camera.

When I think of that day, I realize how much I took Peter's involvement with the children for granted. I have always been the default parent, but through these years of traveling to faraway archaeological sites, innumerable museums, and even Mt. Etna itself, Peter has always been my companion de route. Now I cannot leave Peter alone with more than one child at a time. Slowly, with the help of therapists, we are rebuilding lost skills.

"How is your libido?" every doctor and therapist seemed to ask, adding to the layers of privacy that this injury had stripped from both of us. Even Peter's seventy year-old Qi Gong teacher, who had visited Peter weekly since the accident checked in. "Uh, ok?" Peter would answer, often looking at me for confirmation.

As soon as we were certain that Peter would not actually die, I started to worry about our sex life. We'd only just gotten our post-baby sex life back on track—our youngest was fifteen months; we no longer lived in communal academic housing; we went on regular date nights. Aside from the monumental tasks of recovery from the trauma itself, brain injury can dramatically alter a person's libido, in all kinds of ways. The nurses and I noticed Peter giving an uncharacteristically smirky smile when they lowered his sedation in the ICU and they rushed to check his records for major frontal lobe damage (the kind that can make you pathologically flirty and unable to keep your pants on in public). Although his brain had bounced around a lot, most of the direct impact was to the temporal lobes. The nurses offered me a genuine smile of reassurance.

Once Peter had been discharged to residential rehab, the first step towards coming home, my worry increased. On my drive back to the rehabilitation hospital for my evening visit, I stopped by Good Vibrations, a local sex-positive supply store, and bought two books: the Guide to Sex with Disability, which the salesperson recommended, and a book of erotica. I somehow imagined Peter might read the erotica, with his double-double vision, in between sessions of therapy. In seven weeks, he didn't crack the spine. The erotica sat on his bedside shelf sandwiched between different volumes of easy Sudoku, which we also haven't learned to play.

One night we tried to make out in Peter's rehabilitation room. To facilitate surveillance, his room had a curtain in place of a door, just like my room in my first year of boarding school. Despite years of practice together, we kissed tentatively. Many of the nerves on the right side of Peter's face had been damaged in the impact from his fall, we hadn't gone for more than a peck in months, and neither of us knew what would and would not work. I was nervous, but committed; Peter seemed eager, but not in command. Just as we were finding a groove, a perfunctory knock on the door-frame signaled the arrival of his nurse, Pablo, with Peter's bedtime medications. We broke apart just as Pablo ducked past the curtain. He handed Peter a paper cups filled with pills, winked at me, and sailed out, calling over his shoulder "You must feel like you are sixteen again!"

In late February, Peter came home. As an academic, I naturally signed up for an online sexuality course with a local sex educator. The course included readings, weekly homework assignments, and a weekly Skype session. Having homework was fantastic. I worried that Peter's injuries might have altered the particular landscape of his desires. The course's homework gave me a framework for asking specific questions and experimenting. The weekly skype meetings with the teacher offered a safe space to talk about desire and disability.

I empathized with what Peter might be feeling from my post-partum days. We had not been together long enough before our first child was born for that early haze of lust to have worn off, and then we had a newborn who woke up every two hours. The pitch and roll of all of those postpartum hormones took a long time to settle. We did not have a basis for how to talk about it. Peter was hurt to be rejected, and I was hurt that he had not intuited my need for space. It took ages to excavate ourselves from this cycle of miscommunication.

It was now Peter's body that had changed, his hormones that needed time to regulate, and his muscles that needed time to knit themselves together. I empathized, but I was also frustrated. One friend had just started dating again after a divorce, armed with a sex bucket list, and another friend had just opened up her marriage. I was surrounded by people getting laid. An endocrinologist suggested the age-old recipe for static libido: the more sex you have, the more sex you will want to have. The Qi Gong teacher suggested goat soup and an acupuncture point at the base of the spine. Armed with my homework assignments, we gave it our best shot.

Days after Peter's fall my sister-in-law, who is a therapist, sent me a text that read:

"I trust that Peter is in excellent hands with his doctors and nurses. What are you doing to take care of yourself?"

Her words both touched and alienated me. Peter lingered on a precipice between life and death. Now was certainly not the time to focus on myself, I thought. And yet, days into his ICU stay, a friend who is a massage therapist gave me her time and hands. After that stolen hour at her house, some of my panic eased. There is a strange urgency to the time that a loved one spends in the ICU, although every mechanized breath, shift in heart rate, brain and blood pressure, is measured. Despite this surveillance and Peter's lack of consciousness, I worried about spending any time away from his bedside. One night a seasoned trauma nurse gave me her ICU speech—a pneumonia scare is more likely than not, things often get worse to get better, this is a marathon and not a sprint. That last running analogy is one that I heard again and again throughout the hospital. I struggle with how to pace myself for a run of unknown duration.

A year after the accident, all of my resources have dwindled. Understandably the many friends who rallied to our aid have re-focused on their own lives. Friends have had babies, published books, and made career moves. They've also faced their own

challenges, and I feel ill-equipped to be the friend I wish to be in these moments. Each indicator that other people's lives are moving on jolts me from what feels like stasis. That is not really the correct word for our lives right now because so much is always happening—ophthalmologist, physical therapist, soccer practice, trauma therapist for our oldest child, rock band land, trauma therapist for our middle child, school drop-off or pick-up, follow-up with neurologist, neurosurgeon, neuro-psychiatrist, ear/nose/throat specialist, physiatrist,—but once we reached the visible milestones—walking, talking, homecoming, working—our lives took on a duller sheen. I suspect, however, that this less obvious space is where the truly hard work unfolds.

For years our lives moved so swiftly—every year a new city, every few a new baby, endless research trips, new languages, new jobs, new friends—and we are now struggling to accommodate ourselves to a different pace. Every word and action requires so much more effort for Peter that the act of being out in the world, with its noise, jostling bodies, and quotidian hazards, takes his full concentration.

Peter returned to work seven months after his fall, encouraged by his colleagues at CloudPassage. This choice was right for many reasons: so much of Peter's identity is built around his computer work and the only way to rehabilitate those skills is to use them, Peter's co-workers remained loyal to him throughout his long hospitalization, even though seven months in the life of a start up is a lifetime. The part of his brain that handles complex backend operations has emerged far less scathed than the part that handles complex frontend emotions. That Peter is back at work, however, has become a kind of false short-hand for him being ok.

He works because most days I drive him to and from the office. My own work has taken a back seat to rebuilding our family. Like many women, I fit work into the interstices of therapies, playdates, and cobbled together childcare, often falling asleep at the keyboard only to wake up before the sun in search of a quiet moment. On the other hand, that cliché about necessity and invention has proven true. Since Peter's accident my career has taken a slower, but more creative path and one to which I've held on because work is one important part of my identity.

In December my neighbor invited me to church to make a wreath. We haven't been regular churchgoers, but I thought it might be nice to make a wreath with friends. My Unitarian upbringing gave me an appreciation for most spiritual spaces. After the service the children wanted to go to Sunday school and I somehow found myself in the parents' meeting with my neighbor, another friend, and five other people whom I'd never met.

We were asked to take a stone from a bowl. Each person then placed his or her stone into a vase in the center of the table to release their burdens. I began to cry, for the first time since Peter's accident. I could not stop. I gripped my stone. Someone passed me a box of tissues. The woman to my right, another neighbor with her newborn in tow, twined her fingers with mine. If I concentrate, I can recall the

care that I felt in her touch. Finally, after everyone else had gone, I placed my stone in the vase.

One thing that I have done for myself, almost from the beginning, is to carve out time to exercise. As a young girl, competitive rowing had taught me to value my body less for how it looked than for what it could do and I needed that same sense of capability now. Exercise has always brought me up, but in the years after having children, I'd let that need go. Once Peter was out of the ICU, I started exercising again, not as often as I once had, but regularly. On the day of and after concentrated exercise, I feel calm and able to manage this crisis. If too many days intervene, panic arises. I grow shrill and easily angered. My body has grown stronger. When you are a caregiver, sick days aren't an option because there is no one else. I have slowly come to realize that taking care of myself is one part of taking care of everyone else.

A friend wrote me recently with news of her own recent health issues. In addition to my worry for her, I felt so grateful that she sought me out. A strange, but unsurprising, result of the aftermath of so extreme an accident is that friends hesitate to share their own burdens, as though it cannot compare, or they do not wish to add to mine. Shared vulnerability is one hallmark of intimacy and without it I've found that I feel particularly alone, not because I think that no one else is suffering or overcoming challenges, but because friends now hesitate to share their own worries with me, and I have little time for rituals like a shared drink over which these might more organically unfold.

While our problems feel extreme at times, this accident has compounded a series of quotidian stresses that most people face at one time or another—maintaining intimacy in a long-term relationship, co-parenting through adversity with different styles, helping children process difficult experiences safely, knowing when to seek outside help, balancing work, family, and identity, figuring out how to pay for everything, feeling good-enough, making time for friendships, planning for the future while living in the moment. For us these challenges are stacked like Matryoshka dolls, one emerging from the next, with little space between.

Each day brings a new insurmountable bill, another child's tantrum or rage, more unfinished work, unwritten thank-you notes, or vegetable-less meals. The amount of help that friends have extended humbles me, yet we still fall short. The children feel it too; they've wondered aloud if they, or I, did something to cause this accident to happen.

I do not *want* to be this new version of us, but I am trying to overcome the desire to keep pretending that we are who we were before Peter's accident. One of the children's trauma therapists said something difficult, but important to hear: If you do not live in this life right now, you will never get to the places that you are imagining. Every part of my body tightened in resistance at her words as she said them, but I hear their truth.

One morning Astrid and I turn past the General—Papa’s hospital—on our way home. I slow for the pedestrian mix of visitors, doctors, nurses, and patients crossing to the shuttle. From her seat Astrid exclaims:

“Papa is alive!”

“Papa is alive!” I respond with enthusiasm. And then she carries down her list as a call and response:

“Mama is alive!”

“Soren is alive!”

“Lilith is alive!”

“Astrid is alive!”

And in this moment, I know that we exist.