

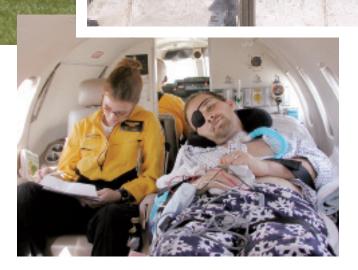




Above right, smiling on a pumpkin-picking expedition in 2003; near right, playing baseball six months before his stroke; below, Kelly stands on a bluff along the Oregon Coast.

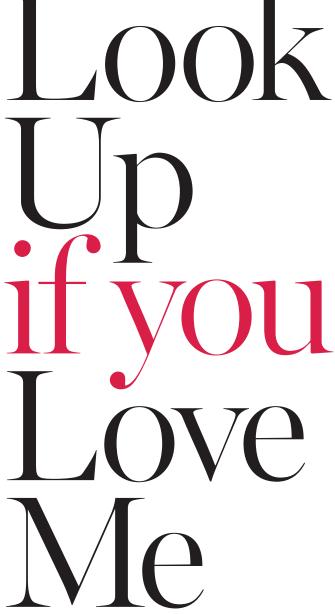


HIS JOURNEY
At right, Kelly being transported by jet to a hospital in San Francisco, 33 days after his stroke; above right, doing swimming therapy with me just eight months later.



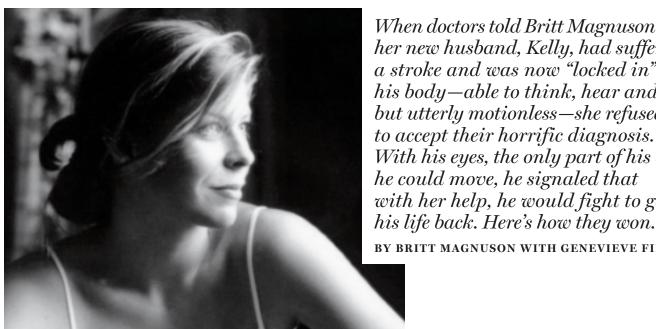
STILL IN DANGER Kelly in a neuro intensive care unit one week after his stroke

PROGRESS At right, we were in a celebratory mood after a successful physical therapy session.



When doctors told Britt Magnuson that her new husband, Kelly, had suffered a stroke and was now "locked in" his body—able to think, hear and feel, but utterly motionless—she refused to accept their horrific diagnosis. With his eyes, the only part of his body he could move, he signaled that with her help, he would fight to get

BY BRITT MAGNUSON WITH GENEVIEVE FIELD



US, CLOSE UP At left, Kelly wearing the eye patch that eased his double vision; below, me the month before I met Kelly



WHEN I FIRST met my husband, Kelly Corliss, in 2001, I had just moved to Portland, Oregon, after an eight-year stint in Paris. At 32, I was getting over a breakup and struggling to establish a photography career in the United States. The last thing I expected when I walked into a Kinko's was to be swept off my feet by the guy working behind the counter. But here was this 6'2", strapping, handsome young man, bouncing around and singing German opera in the clearest, most beautiful voice—what girl wouldn't be a little smitten? We laughed for the next hour straight, and I left with plans to meet him sometime soon for coffee.

Kelly moved in with me three months later. Our little duplex was always filled with his singing; I learned that his perfect pitch and operatic lungs had won him college scholarships. One of my nicknames for him was The Jukebox; the other was Bear, because when Kelly hugged people—and he hugged everybody—he picked them right up off the ground. He called me Bisou, which means "kiss" in French.

In the summer of 2004, we moved to San Francisco, where I'd enrolled in culinary school. He didn't blink an eye about leaving his friends and family to come with me. After all, he'd been asking me to marry him since the first month we met. I finally said yes, and on December 4, 2004, we eloped on a Northern California beach called Lovers' Point.

Kelly transferred into a job as an assistant manager at a local FedEx Kinko's, where he did the work of three people and drove his bosses crazy with suggestions about how to improve the system. But he'd been a star baseball player in college, and he dreamed of returning to his sport. It wasn't long before he'd joined some local teams and was playing a couple of games a week. He was addictive to watch—a power hitter with a snap in his hips—and in the fall of 2005, one of his teams was invited to Phoenix to play in the National Adult Baseball Association World Series, where pro coaches are known to scout for new talent. The

morning Kelly's team departed for Phoenix, he picked me up, spun me around and said, "This is it, Bisou, this is it."

The next night he left the most amazing message on our answering machine. He was in Joshua Tree, camping with some of his teammates. He'd cooked them all a steak dinner, and then he'd stood on the top of a boulder and sung arias to the stars. I still have his voice on tape saying, "Oh, Bisou, I'm in the most beautiful place, it's magic here, I have to show you this."

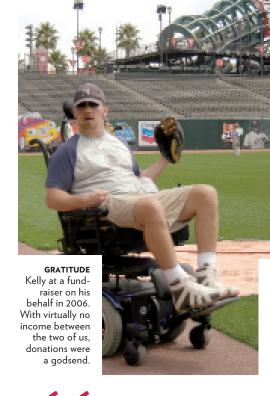
Life, Interrupted

Two days later, on October 5, 2005, I got a call at the restaurant where I was interning. A guy's voice on the other end of the line came rushing at me: "Kelly was playing Wiffle ball with the guys and as he threw the ball he just dropped to the ground and he was scrambling his words and he said he had a headache. We thought he had heatstroke and the ambulance just took him!"

Somehow I knew that this wasn't heatstroke—it was something life-altering. Running out the door, I told the chef, "If I see you anytime soon, I'll be grateful."

By the time I got to his bedside in Phoenix, six hours after that horrible call, he'd already been transferred to a second hospital. A nurse had told me over the phone, "Get on a plane now. He may not make it till you get here," but even that dire warning couldn't have prepared me for what I saw when I burst into Kelly's beeping, whirring hospital room. He was on life support, every breath pumped into him by a machine; his body looked swollen and red, and his eyes were rolling around in his head, as if to say, "Help!"

The doctors couldn't tell me exactly what was wrong with my husband; he wouldn't be correctly diagnosed until he was transferred to a brain injury hospital later that day. There he underwent hours of surgical procedures. When it was over, a doctor approached me with his eyes at half-mast and said, "I'm sorry. We did everything we could given how late we got him." But Kelly hadn't died, he'd had a brain stem stroke. A blood clot had formed in a crucial artery in his neck, interrupting the supply of oxygen-rich blood to his brain stem and eventually causing the stroke. It was a fluke, a freak injury. The doctor explained that they'd managed to restore the blood flow to Kelly's brain, but there were some serious "potentials" I needed to know about.



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Buried Alive

Those "potentials" were unfathomable. The doctor, now flanked by a row of colleagues, explained to me and our families that Kelly's cognitive function seemed undamaged, but his brain stem—the pathway through which the brain sends messages like "walk," "talk" and "breathe" to the rest of the body—had been almost entirely destroyed. He was left with locked-in syndrome, a condition in which the patient is fully lucid and feels all the normal physical sensations, but cannot voluntarily move or speak. I'd read Jean-Dominique Bauby's book, *The Diving Bell and the Butterfly*,





KELLY'S VICTORY Above, on the eve of our first wedding anniversary, when Kellv could barely sit up; left, by spring 2006, Kelly could

so I knew that the classic locked-in patient can communicate only by blinking or moving his eyes up and down, as Kelly had done so frantically when I'd first walked into his hospital room.

But even that window into Kelly could soon disappear, the doctors warned. If Kelly's brain stem continued to swell, the remaining thread of a pathway between his brain and body would close off entirely, and he would lose even the ability to move his eyes. He would essentially become mummified in his body. "If he survives the next 48 to 72 hours," I remember the lead doctor saying, "permanent and total lockin is a very real possibility. The best you can probably hope for is that Kelly will live and regain some small movement."

I stared at the row of white coats in disbelief. No, this was wrong. Kelly would not go this way. There was no question, in my mind at least, that he deserved to be fought for. So I decided then and there that I would challenge the doctors' prognosis and the entire medical system if necessary. They had no idea who they were sentencing. "This is a man with the strength of 10 men," I told Kelly's doctors. "This is a man who could pick up cars by one end. He can beat this."

One of them tried to soothe me, saying he understood how much I loved my husband, but I cut him off.

"I'm not just talking about love here, folks," I said to the doctors. "I'm talking about the fact that you have a locomotive in that bed. He's bigger than this." Then I walked out of that room and never looked back.

Minutes later I climbed onto Kelly's bed, straddled him and looked into his eyes. The amazing life force that had made me fall in love with him was still there. Those eyes were potent, full of energy, full of him. Within seconds we figured out that a glance up meant "yes," and a glance down meant "no." I said, "Can you hear me?" He looked up. "Do you want to know exactly what's going on?" He looked up. I said, "You've had a brain stem stroke," and I gently explained what that meant. Then I said, "I think we can get through this, so I'm going to fight. Are you going to fight with me?" He looked up again, and tears came pouring out of the sides of his eyes. I cried with him that night, but it was the last time I let him see my sadness or fear.

For the next five days and nights, I staved in that room, mostly in Kelly's bed, cradling him on a near-freezing pad of circulating ice water that reduced his risk of swelling. My arm and shoulder would go blue and numb, but I wouldn't pull away from him except to help clean his ventilator, check his medication or move his body every 20 minutes so he wouldn't get bedsores. Lots of other people thought I was a little nuts—I even heard one of the doctors call me delusional. I didn't care; mistakes are made in hospitals every day, and under my watch, they wouldn't happen to Kelly. More important, he had to know I was there so he'd fight with me; I didn't want him to feel alone for even one second.

Breakthroughs

By the third day Kelly's dearest friend, Merry, had moved into Kelly's room with us. They'd been friends since the fourth grade; both phenomenal athletes, they could play Frisbee golf or catch together for hours. She was a tough cookie who came to share my philosophy that optimism was the best medicine for the man we both loved. One day we noticed something remarkable. "Did you see that?" I said. "Yes!" she shrieked. He was taking an extra little breath of his own after each one that the machine pumped into him. His lungs were fighting to be self-sufficient.

Over the next two weeks, a metamorphosis took place: Kelly's oxygen supply was gradually turned down. His temperature stabilized, and the bed of ice was taken away. Then, out of the blue, the edge of his upper lip began curling up mischievously. When Merry and I shouted, "He's smiling! He's smiling!" his eyes flashed upward to say, "I am!"

By this time we had figured out how to communicate with an alphabet board. Merry or I would point to or call out letters on the board until he glanced up to signal "yes," spelling out shorthand words and sentences. When the two of us were alone, he liked to spell out racy notes to me.

October, 2005: I wnt u on top.

He wasn't kidding: About three weeks into our hospital stay, I was giving Kelly a massage to stimulate his circulation, and up went the bedsheets-his first poststroke erection. He looked at me with that lopsided smile, now dubbed "the Elvis"and asked me with his eyes if I'd like to do something about it. "I'd have to get permission," I said. "No," he spelled out, half joking. "If it kills me, it'll be a great way to go." I did get a doctor's OK, and soon I was hanging a do not disturb sign on our door as often as we could get away with it. Some of the nurses later told me that it was probably thanks to our sex life that Kelly regained nerve control and urinary function down there more quickly than any other stroke patient they'd seen. And of course, I knew it did wonders for his mental health to be part of the physical world again in this way. But the most poignant thing about our lovemaking was the possibility that I might get pregnant. We'd never tried to conceive before, but now we couldn't help imagining the motivation and hope that a child might bring. And though we never said so, I think we both found peace in the idea that if Kelly didn't live through this, he might leave a part of himself behind.

After 33 days in that Phoenix hospital, it was time for Kelly to be moved back to California, where Medi-Cal would cover his care. Kellyhad Continued on page 212

Locked-in continued from page 201

left his job—and lost his insurance—five months before his stroke, so we searched frantically before finding a hospital in San Francisco willing to accept him in their intensive recovery program. There he continued to defy the entire medical community's expectations. Within three months he not only was breathing on his own but could also make attention-getting squeaks and grunts, and type and manipulate a computer mouse with his thumb.

He began documenting his recovery in occasional e-mail updates to the devoted family and friends who made up what we called "Team Kelly." Mostly he expressed gratitude for their visits and donations, and he was particularly effusive about his appreciation for me.

November, 2005: My body and voice have been taken away from me—if they were ever mine in the first place. I realize that things could be worse. I've lost many gifts, but I still have Britt. And I have to remember: I'm not the only one going through this; so is she, my partner.

Sometimes I would catch Kelly crying as he watched me preparing his meals. Having vetoed his prescribed diet of liquid Ensure, I'd set up a kitchen in Kelly's room so I could pump his feeding tube full of the best nutrition possible: yogurt, tofu, berries, spirulina, even chicken soup. Meanwhile, he worked intently to relearn how to swallow without choking so he could one day taste real food again—another of the hundreds of things they said he'd never do.

A Life Against All Odds

When Kelly was discharged from the hospital, all of his care was suddenly in my hands. I'd found us a ground floor apartment in Napa, California, and the state would eventually pay me \$10 an hour to be Kelly's caregiver-my new full-time job. That stipend was what we would be living on, plus my credit cards, gifts from family and friends, and proceeds from fund-raisers. Although I tried never to show it, I was terrified. I was a 5'8", 150-pound woman caring for a 250-pound quadriplegic 24/7-lifting him, feeding him, washing him, transporting him. I didn't realize how much it had exhausted me until I took him to physical therapy one day and almost passed out in the hospital lobby. An angel dressed as a

therapist admitted us both into the hospital. I stayed overnight, and Kelly stayed for the next two weeks, allowing me to unpack and get a little strength back. He kept my tired spirits up by sending me a constant string of thumb-typed e-mails.

January 31, 2006: Britt, Iloveyou. Thank you for taking care of my crippled ass. Love, K

On one of those chilly nights while I was alone, Merry took me out to hear some music and have some drinks. It felt great, for a while. Merry kept refilling my wineglass, and we started to dance. But out on that dance floor, the tsunami wave of emotions I'd been holding at bay for so long finally hit me; it came on with such force that I panicked and ran out of the club. Merry found me down the street, holding on to a tree so hard that my hands were cut and bleeding. I remember feeling that if I let go, I'd be swept away and disappear forever. Eventually Merry peeled me off, took me home and put me to bed. I remember her telling me, "It's OK to be human. It's OK to be sad."

Kelly's emotional surges were just as powerful. He'd been on heavy doses of antidepressants in the hospital, and the doctors were now tapering him down. For the first time since the stroke, he could really feel his frustration and anger—we could both feel it.

February 16, 2006: I'm too much for one person to care for. Britt took on too much. But be on the lookout for me, because I'm pissed. I'm pissed about a lot of things: not being able to chomp into a burrito, not being able to make love to my wife the way I want to, not being able to tell my parents I love them, not being able to sing.

Despite it all, our strange new life together had moments of real happiness and tranquility. We'd stretch out on the floor on pillows and watch old movies; we'd take walks at night with the wheelchair and listen to the crickets and the frogs. It was on one of those regular nights that Kelly truly broke out. I was transferring him from his chair when I noticed he was gripping the counter with all his might. I said, "You want me to let go?" His eyes said yes, so I did, and miraculously, he straightened his spine and, legs trembling, stayed up. My God, we had climbed Mount Everest.

After that victory, Kelly tackled his physical therapy with a renewed intensity, willing his body to do the impossible.

April 19, 2006: I can honestly say that things in life came easy for me, but not

Kelly's Message to You

What everyone should know about recognizing and treating a stroke

Strokes can happen to anyone. Nearly 30 percent of stroke victims are younger than 65. Timely treatment dramatically decreases the risk of death or disability. If you've suffered the most common kind of stroke, administration of the blood-clot buster tPA within three hours of the first symptoms could significantly reduce your odds of a disability. I didn't get that treatment quickly enough, and I'll always wonder what might have been if I had. Watch out for sudden onset of any of the following symptoms, and then get the right care. 99

- Numbness or weakness of the face, arms or legs
- Confusion, or trouble speaking or understanding others
- Trouble seeing in one or both eyes
- Trouble walking, dizziness or loss of balance or coordination
- Severe headache with no known cause

If you or anyone close to you experiences these symptoms, call 911 immediately and ask for an ambulance for a possible stroke victim. For more information on treatment, go to stroke.org.

now. I stood in a standing frame for an hour today. I had to unclip some colored clips from a vertical ruler. All the years of sports have taught me to compete to the death if that's what it takes to win, but reaching for those clips, and this entire process, has given me something I didn't have before: humility.

Then, in December 2006, we were buoyed by the news that I was pregnant. It was a giddy, surreal time. I didn't know exactly how I was going to care for a quadriplegic and an infant all by myself, but I'd come to believe I could do anything. Kelly celebrated by relearning to eat and becoming more and more verbal. The words came out in a high-pitched drawl because he had very little voice or tongue control; I was one of the few who could understand him. Life was a difficult balance, but as Kelly wrote on his blog, there was much to be hopeful about.

December 2006: May the sun heat our tired, wet bones and may the grapes grow plump. Today is my day off from therapies, so I'll stay up late and Britt and I will sleep in and eat leftovers. Aren't I lucky to be alive? Yes, yes, I am.

Dark Days

I spent Christmas Day 2006 nauseated and dozing on the couch. Kelly was worried about me, but I told him I'd be fine if I could just sleep. And I did-for 48 hours-but on December 29 I started to bleed heavily; it was unmistakably the start of a miscarriage. I was plunged into mourning, and Kelly was truly wrecked. He said if I hadn't been taking care of him and moving him around, it wouldn't have happened. I insisted that we couldn't possibly know why the pregnancy hadn't taken, but there was no reaching him; he descended into full-blown depression. He stopped fighting for himself-I had to coax him to try to stand and walk, to take his medications, even to drink water on his own. Instead of writing updates to Team Kelly in his free time, he played video games for hours on end.

Twice over the next several months, we tried spending time apart. Kelly would visit his parents; I would stay home and attempt to recharge so I could motivate him again. But the separations left Kelly even more despondent. One night he drove his wheelchair out into the darkness, wordlessly threatening to throw himself into a stream. We hit the breaking point when Kelly tried to suffocate himself; I still shiver thinking about what might have happened if I hadn't woken up and found him. The paramedics who arrived minutes later told me I was lucky. Afterward I said to Kelly, "If you're going to make these kinds of choices, I can't live with it. I'm falling apart." Since the miscarriage, I'd lost 20 pounds, and I felt like I had aged 10 years. Kelly looked at me, really looked at me, for the first time in way too long, and started to cry.

His parents arrived two days later, pulling a trailer to carry away their son's belongings. Kelly explained his decision to move out in his halting new voice: "This is for both of us. You need to get better, and I need to fight for my recovery. Nobody else. I have to choose it. Otherwise I'll never know what I'm made of." Of all the gutsy things he had done over the past 20 months, leaving me had to be the gutsiest.

The minute they drove away, I collapsed, crying out my sadness and terror about what would happen to Kelly without me. And for the next 100 nights or so, I'd awaken every few hours to check his breathing or help him turn over, only to feel the empty space beside me. It helped that we stayed in fairly constant contact, exchanging hundreds of instant messages, a medium he preferred to the phone.

April, 2007: Wow, little did I know that losing my voice and physical ability would be nothing compared to losing you. I've hit rock bottom, but when you sink as low as you can go, there is only one direction you can go from there. Well, really there is another, but that's the cowardly way, and we both know I couldn't stand for that.

That was one of his more positive messages—in others, he sounded borderline suicidal again. Part of me wanted to make it work, but I realized that if I returned to our marriage, I'd lose myself in caring for Kelly, and he would lose himself in dependency. I told him we needed to stay apart. Eventually his messages stopped coming altogether. I tried to take it as a good sign—

I'm doing it now, Britt: fighting for my recovery like you always wanted.

that he was moving forward—but I was worried sick. And then just after Christmas, I received the letter that set me free.

December 29, 2007: I'm doing it now, Britt: fighting for my recovery like you always wanted me to do. It is not to spite you but inspired by you. I will love you forever, but I need to let you go once and for all now. Be certain that I will be OK.

Always Connected

In the end, you could say our marriage was the ultimate victim of the stroke. Our journey together on what we called "the rocket ship from hell" changed the fundamental nature of our relationship-from husband and wife to patient and caregiver-and for us, there's no going back. But Kelly himself is no longer a victim—he's one of only a few people in the world who've beaten lockedin syndrome. It made me so proud when he wrote to me, "I value what you fought to preserve: my life." Of course the new Kelly is still a work in progress. Over e-mail, he tells me that with his parents' support, he can walk the length of two football fields. He's taking classes and making stroke awareness presentations at schools. In the mornings he rolls out on his deck and sings "in a different way" to the world.

As for me, I recently moved to New York City to pursue photography and journalism. I'm chipping away at the debt I racked up while I was a full-time caregiver. I'm eating well, sleeping well, and trying not to check Kelly's website too often. With his support, I'm fighting for myself the way I fought for him. As he wrote in another letter: "I am thankful that you are free to live a full life. You have the strength of wild horses. Goodbye, and live, have fun!" That's what I'm trying to do.

Talking about this story has brought Kelly and me closer than we've been since the day we separated. We've both noticed that being in touch gives us each a sense of peace and balance. A part of me will always be with Kelly. For two years I invested 100 percent of myself in keeping the man I loved alive. And now, whenever he communicates positive things to me, I'm reminded that I've done something great for somebody. Helping Kelly to reclaim his life—that's my proudest achievement. ■

Britt Magnuson is a photographer and writer living in New York City. Kelly Corliss lives in Grants Pass, Oregon. Learn more about him at kellycorliss.com.