

Doctors wanted to take me off life support—but I was conscious the whole time

The patient was in a coma—all the doctors said so. The only one who disagreed? The patient

Tom Hallman
RD

Richard Marsh awakened to the rhythmic beeping of a machine. Something was lodged in his throat. He couldn't cough. He couldn't sit up. He couldn't move.

What's going on?

He tried to move his legs, arms, and fingers. Even his eyeballs, he realized, wouldn't budge. He felt someone put drops in them to keep them moist, but he couldn't make out who it was.

What's wrong with me?

He could only stare in one direction—straight ahead. With his peripheral vision, Richard could see his wife off to his right. He heard her talking to a man next to her, a man who seemed to be in surgical scrubs.

"It doesn't look good," the man said.

What doesn't look good?

"His chance of survival is very small."

They're talking about me.

Richard willed his body to respond: with his voice, his eyes, his hand. Nothing.

"You need to prepare for the worst," the man in scrubs told Richard's wife, Liliana Garcia. Though somber, she didn't cry. A registered nurse at a hospice center, she quickly turned professional, asking the doctor clinical questions as if the man in the bed were just another patient, not the love of her life.

I'm in here.

And then his world faded to black.



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He hadn't felt well two mornings before. Liliana noticed he looked a little pale. But Richard didn't want her hovering and fussing over him as if he were her patient. He said he'd be fine and insisted she go to work. That was his way. Once alone, Richard relaxed on the couch before he had to leave for school. He taught forensic science and economics near his home in Napa, California, and he was considered one of the high school's popular teachers.

He stood up, ready to leave for work, when he felt as if he were on the deck of a small boat in choppy seas. He grabbed the edge of a table and made his way to the telephone. He called his wife's office and left a message for her to call him.

Richard sat back in a chair at his desk. Something was wrong with him. He rarely drank, never smoked, and he really was in great shape. At 60 years old, he stood six feet two inches tall and weighed 215 pounds. He pumped iron at the gym, a habit he'd started during his first career, as a police officer. The phone rang—Liliana calling him back. "Come home," he told her.

All Liliana heard was a garbled voice. Then she called 911.

Minutes later, Richard was rushed to the hospital in an ambulance. Numbness had

started in his feet and crept up his legs to his waist. He felt himself losing control of his muscles. He couldn't swallow. To save him, an ER team put him under and inserted a breathing tube down his throat. He was then given medication to fight a stroke that doctors believed was being caused by a clot. (These are silent signs of a stroke that you could be ignoring.)

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After doctors did what they could, nurses wheeled Richard to intensive care. And then they waited.

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Once he had awakened, even though he was paralyzed, Richard felt sensations when doctors and nurses touched him.

I don't feel sick. I just can't move.

Slowly, he realized he was trapped in a prison that was his body. He heard the doctor explain to Liliana that her husband was in a coma. Richard heard the blunt diagnosis: a 2 percent survival rate. "If he lives, expect severe brain damage ... Little hope ... Best outcome is that he survives but lingers in a vegetative state ... You need to consider taking him off life support," Richard recalls hearing the doctor say.

He remembered the conversation he and Liliana had had three years earlier, when they got married. They discussed end-of-life scenarios. They agreed that if, God forbid, either of them required life support for whatever reason, the other spouse needed to pull the plug, out of compassion and love. Richard heard his daughters' voices. Distant. Perhaps in a hallway? Liliana told the doctor she needed to discuss the issue with her husband's daughters, adult children from a previous marriage.

I guess I'm dying.

Liliana returned. The family, she told the doctor, had agreed to wait a few days to see

how Richard progressed. The girls, she explained, weren't ready to let their father go. Nor was she prepared to lose her husband. Throughout the day, friends came and stood by Richard's bed. They talked about old times. They told him they loved him and how good he looked.

His daughters came with the grandkids. As they leaned toward his face, Richard saw the tears in their eyes, even as they shared words of encouragement.

No. I'm here!

He felt lips on his forehead. A character in a macabre scene in a horror movie, Richard had only his thoughts to keep him occupied. He'd never go home again, teach, or kiss his wife. He'd lie in a hospital bed—the ultimate solitary confinement—for years. Or his family would sign the papers and wait by his side as the doctors did what was necessary to let him slip away.

Richard heard the staff talking and laughing in the hallway. Life, the every-day life he'd taken for granted, was so close and yet so far away. Perhaps death would be a blessing, he concluded. Richard accepted the inevitable. He resigned himself to the end.

If it's going to happen, let it happen.

The next morning, a neurologist stopped in the ICU and huddled with other doctors at his bedside. Richard heard part of the conversation: "Has anyone checked to see if he's in there?"

The neurologist leaned over, so close that Richard could feel the man's breath on his cheek: "Rich, if you can hear me, blink your eyes."

Blink ... Try ...

When Richard was a cop, he was trained to deal with scary events head-on. But now ... What if he couldn't blink? He drew on the cop inside, the strong man, the rock. He was good with victims, those suffering tremendous loss. In this instance, Richard Marsh was the victim. Content continues below ad

Blink!

And then ... a blink so excruciatingly slow that the neurologist couldn't be sure what he'd seen.

"Rich, blink your eyes again. Can you hear me?"

A ... blink.

They knew.

* * *

Extensive tests revealed that Richard had suffered from a congenital anomaly in one of two arteries in his brain. One artery was fully formed but blocked. The other artery had never formed, an undiagnosed birth defect that hadn't caused Richard problems until now.

With the blood supply compromised by that blockage, Richard had suffered a brain stem stroke. The stem, which connects the brain to the spinal cord, controls nearly all bodily functions. His heart was beating, but there was virtually nothing that Richard could voluntarily will his body to do.

With Liliana by his side, doctors explained that Richard suffered from "locked-in syndrome," meaning he was literally locked in his body. They asked him questions: Blink once for yes, twice for no. It took extraordinary effort for Richard to get his eyes to work.

Up to 70 percent of people diagnosed with the syndrome die within a short period of time. Of those who do survive, only a handful recover enough to lead a normal life.

But before he could even hope for such an outcome, Richard would have to endure new terrors.

* * *

Richard was moved from the ICU to a hospital where specialists would let his body decide the course of the treatment. Because he could not swallow, doctors performed a

tracheotomy, making an incision in his windpipe and inserting a tube so Richard could breathe and nurses could suction out the saliva that would otherwise drain into his lungs.

Horrible. But they know I'm here.

To help Richard communicate more easily, Liliana bought a letter board for the family to hold in front of him. The board had four quadrants, each containing several lines with five letters in each line, and an empty box in the middle to write his message in. Richard would look at the board. His family would have to follow his eyes to the correct quadrant.

This corner? A blink.

First line? Two blinks.

This letter? Two blinks.

Second line? Blink.

This letter? Two blinks.

Every word, slowly spelled out.

As tough as the days were, the nights, after his family had gone home, were hell. The staff didn't use the board, nor were they constantly around to take care of his every need.

Trapped, Richard was alone and scared. Fluids built up in his throat, choking him, and no one was around to suction them out for him. His roommate heard him struggling to breathe and used his call button to get the nurses to help.

When his family arrived one morning, Richard looked wildly at the letter board. Slowly, he made his wishes known: Get me out of here. Days later, his wife moved him to a hospital closer to their home. Physical and occupational therapists started to work with him more aggressively, trying to get his body to function fully again.

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Days passed.

There's no returning to normal.

Then weeks.

Hardest thing I've done in my life.

Then one day it happened—Richard moved the big toe on his left foot. Two weeks later, he moved his head side to side. Days later, he wiggled a foot. After another day or two had passed, he could shake his legs. His family members cried, laughed, and hugged one another with each new victory. More than two months after his locked-in diagnosis, Richard did something he'd taken for granted his entire life—he raised his hand and touched his nose. And then he walked, a big toddler taking the first few wobbly steps, rocking from side to side with his walker to keep his balance as he slowly made his way from his bed to the door of his room and back, a therapist close by his side in case he fell. Exactly four months and nine days after the stroke, after more painful and painstaking rehab, Richard Marsh walked through the front door of his home under his own power. He sat in his chair. He was back.

* * *

Richard was forever changed. He'd lost 50 pounds of muscle, and when he came home he was so weak that he couldn't lift a carton of milk. Physically, he rebuilt his life. It took a year, but he returned to his fighting weight, back pumping iron at the gym. Emotionally, Richard no longer got easily irritated or worried over the little things. He became less controlling. He even retired from teaching and took over the household duties while Liliana continued to work. He found pleasure in life's simplicity. Someone gave him the book *The Diving Bell and the Butterfly*, the memoir of Jean-Dominique Bauby, a journalist who suffered a stroke and remained locked in for the rest of his life. Bauby dictated his story to his publisher's editorial assistant by blinking his one good eye in response to an alphabet rearranged by how often letters are used. He died two days after the book was published.

Richard read two chapters and promptly gave the book away. Unlike Bauby, Richard was very much alive.

He would never forget waking up in the ICU and the long journey to escape his prison. He'd been given a second chance, a precious second chance. He vowed, daily, to never squander the gift.