

When the seizures wouldn't stop

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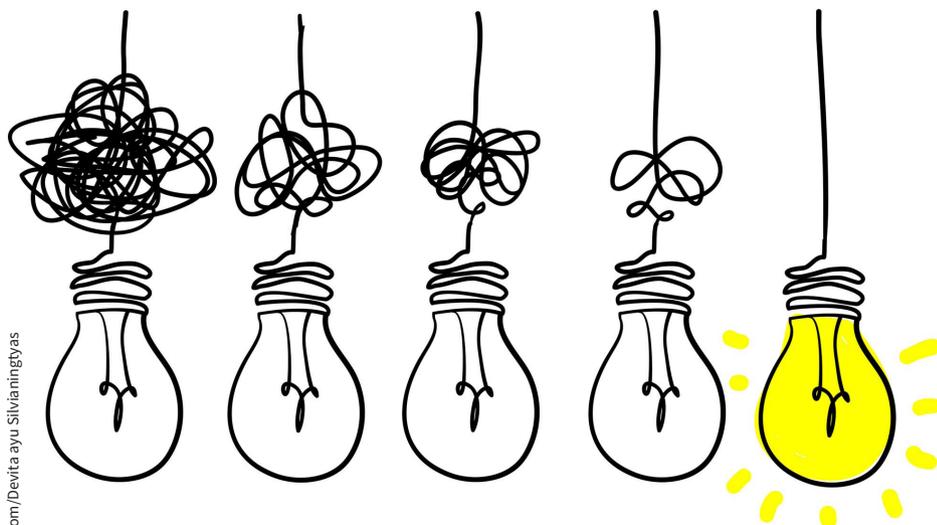
Earlier this year, we admitted a patient named Jorge into our intensive care unit (ICU). Jorge had complained to his daughter, Marie, of muscle pain. It hurt him to walk and even to stand. He was more tired than usual, often sleeping for hours at a time. This had gone on for weeks.

"Then he had what I thought was a seizure," said Marie the night her father was admitted to us.

In fact, he'd had several of them. He was rushed to the hospital, where blood work revealed severe muscle breakdown and acute kidney injury, but no convincing trigger for his seizures. A computed tomography (CT) scan of his head showed no acute abnormalities. He was admitted to the ward, treated with intravenous fluids, and his kidney function slowly improved. Things seemed to be getting better.

But that night, a resident on the medicine ward contacted the ICU outreach team because Jorge was in status epilepticus. We loaded Jorge with intravenous anti-epileptics and rushed him to the ICU, where he had another generalized seizure. We pushed boluses of drugs and intubated him. And in that ensuing stillness that is the common fate of many critically ill patients — where their breath is no longer theirs to command, and their thrashing is reduced to a stir — it seemed as if we had finally broken Jorge's seizures.

What followed was a battery of scans and blood tests — the full workup, expedited by our fear that Jorge's stillness would not last. We performed another CT scan of his head (no change), more blood work (normal) and a lumbar puncture (mildly elevated protein count), and started continuous electroencephalogram monitoring. This showed he was still having seizures, but the cause was not



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clear. We sent blood cultures and a full metabolic workup. A magnetic resonance imaging scan could not be performed because one of his medical devices was incompatible with the scanner.

"I was worried," Marie later said. "But I also knew he was in the right place. The ICU was exactly where he needed to be."

Marie was speaking from a place of experience. Having seen her mother survive multiple admissions to the ICU with life-threatening complications from lupus, she had been left with a powerful hope about what the ICU could achieve. It was only natural to see those hopes now extended to her father. But as the initial hours of Jorge's admission turned into days, we found it challenging to maintain our own optimism. For all our effort, we were no closer to finding a diagnosis, even as our search led us toward more fanciful and far-reaching possibilities. Meanwhile, the patient for whom all this was being done was oblivious to all of it. As Jorge lay in bed, his eyes closed, mouth open, it

was difficult to imagine that he had once been, in the words of his daughter, "a man full of life."

In the ICU, we often care for patients like Jorge, who remain stuck in a limbo and appear not to be progressing meaningfully in any direction. As time passes, an uncomfortable truth begins to set in: the urgency we once felt toward their case begins to fade away. Like a seizure that finally comes to an end, our efforts lose their previous vigour and we become increasingly prone to cynicism. Do we sincerely believe that the next CT scan or lumbar puncture will reveal a clue that the previous ones did not? Will a brain biopsy really suggest the answer, or will it merely provoke a futile chase in the wrong direction? Such questions have no clear answers, and in these moments, it becomes tempting to distract oneself with the smaller matters of ICU care: fixing glucose levels, choosing between fluids and furosemide, or ordering venous thromboprophylaxis.

As time went on, a diagnosis remained as elusive as ever. Meanwhile, the weeks in the ICU began to take their toll on Jorge. First, he developed ventilator-associated pneumonia, then a urinary tract infection. His muscles shrank, and bruises appeared on his arms and legs. Watching his body unravel, we believed with increasing certainty that he would not survive. We were afraid of how the news would affect Marie, and with each passing week, the dread of this unspoken reality grew — to the point where fixing blood work and adjusting medications became more than a distraction: it became our refuge. It is said that patients who do not get better remind us of all the missed opportunities, errors of judgment, or simply unavoidable misfortunes that brought them to us in the first place. In the ICU, such patients can make clinicians uncomfortable. Rounds at their bedside are quick and perfunctory. Notes are brief, teaching is kept to a minimum, and even eye contact with patients and their families — the most primal of acknowledgements — can be missing. There are other patients to see, with unsolved problems of their own, and one can't help but feel that one's efforts would be better spent elsewhere.

"I knew things weren't getting better," Marie later said. "But I still hoped you hadn't given up on him."

In Jorge's case, what reinvigorated our hope and prevented our ennui from becoming entrenched was the calculated decision to try something dramatically

different, at a time when the odds of an unfavourable outcome seemed all but guaranteed. Now many weeks into Jorge's ICU stay, with the seizures not yet fully extinguished, we decided to trial a course of pulse steroids. We explained to Marie that perhaps her father had a case of autoimmune encephalitis, which our repeatedly negative antibody screen had not identified. If the pulse steroids produced a clinical response, we would continue the steroids at a lower dose and consider a treatment of intravenous immunoglobulin. It was not clear if this would work, but when the alternatives included either life in a moribund state or transition to palliative care, we felt compelled to try.

So did Marie. As she later explained, what mattered to her was knowing that we remained committed. And she took great solace in this, because the humdrum routine of fiddling with drugs and ventilator settings — a common fallback for the overwhelmed intensivist — offered no answers to her deeper uncertainties. More important than our decision to prescribe steroids was the simple message it conveyed: that we had not forgotten about Jorge. Feeling forgotten could often be the cause of a loved one's frustration and guilt, resentment and avoidance behaviours. With Marie, we judged that steroids were a simple and relatively benign intervention that fulfilled a therapeutic but also emotional obligation. Sometimes, however, it is the emotional obligation that families desire most. This does not necessarily require us to "do more" or

"push harder," but maybe just take an extra minute with a family member on rounds, or inquire about a loved one's life before their illness.

Six months later, I bumped into Marie in the cafeteria of the hospital. There was chatter in the lunch lines and the tables were crammed with their usual patrons. Marie waved me down when she saw me; I almost hadn't recognized her removed from her father's bedside, without ventilators and IV poles serving as the backdrop to our interactions. But I was even more surprised to see the person sharing her table. Seated in a wheelchair, with his tracheostomy out, intravenous lines disconnected, hair neatly trimmed, and looking very much like "a man full of life" as Marie had once described him, was her dad, Jorge.

"Hello," he said, through a mouthful of pizza.

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This article has been peer reviewed.

This is a true story. The patient has given his consent for this story to be told. His name, and that of his daughter, have been changed to provide anonymity.