

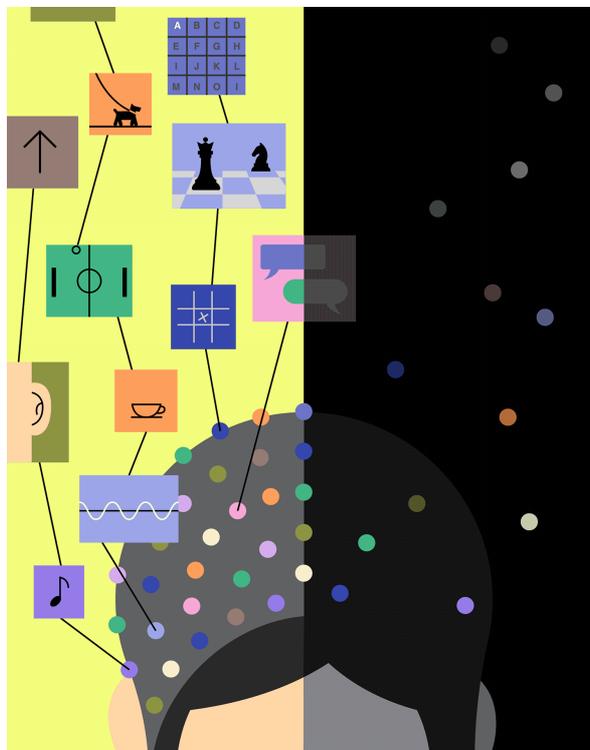
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DO BRAIN IMPLANTS CHANGE YOUR IDENTITY?

As neural devices proliferate, so do reports of personality changes, foundering relationships, and people who want to leave their careers.

By Christine Kenneally

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Studies show that people with neural devices can experience shifts in identity. Illustration by Annie Jen



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The first thing that Rita Leggett saw when she regained consciousness was a pair of piercing blue eyes peering curiously into hers. “I know you, don’t I?” she said. The man with the blue eyes replied, “Yes, you do.” But he didn’t say anything else, and for a while Leggett just wondered and stared. Then it came to her: “You’re my surgeon!”

It was November, 2010, and Leggett had just undergone neurosurgery at the Royal Melbourne Hospital. She recalled a surge of loneliness as she waited alone in a hotel room the night before the operation and the fear she felt when she entered the operating room. She'd worried about the surgeon cutting off her waist-length hair. What am I doing in here? she'd thought. But just before the anesthetic took hold, she recalled, she had said to herself, "I deserve this."

Leggett was forty-nine years old and had suffered from epilepsy since she was born. During the operation, her surgeon, Andrew Morokoff, had placed an experimental device inside her skull, part of a brain-computer interface that, it was hoped, would be able to predict when she was about to have a seizure. The device, developed by a Seattle company called NeuroVista, had entered a trial stage known in medical research as "first in human." A research team drawn from three prominent epilepsy centers based in Melbourne had selected fifteen patients to test the device. Leggett was Patient 14.

Her seizures had taken many forms. At school, she would zone out, coming to only when a teacher threw something at her or her classmates jeered. Once, as an adult, she was drying dishes when, with a small shout and no warning, she sent a dinner plate flying into the air and then, oddly, managed to catch it again. Not all the seizures were so mild. There was a time when she fell down some stairs and awoke days later in the hospital, her jaw so badly broken that surgeons had had to take a piece of her rib to reconstruct it. Leggett was a single mother of four children, and, another time that she was hospitalized after a violent seizure, her teen-age sons were accused of having beaten her up.

When Leggett's neurologist asked if she wanted to participate in the NeuroVista trial, she didn't hesitate. Two months later, she was in the operating room having a small hole drilled in her skull. Morokoff had carefully braided her hair, so that she would lose as little as possible. Once he had made the hole, he slid a cross-shaped silicone strip inside and laid it across the surface of her brain. The strip was studded with sixteen electrodes, and Morokoff ran wires from them under Leggett's skin, behind her ear and down her neck to connect with a device that he implanted in her chest. This device would receive the data recording Leggett's neural activity and transmit it wirelessly to an external processing unit, which she was supposed to keep with her at all times.

The external unit was the size of two flip phones stacked together, and it took some getting used to. If the system predicted that a seizure was imminent, the unit would warn her with a red light and a beep, though she found the beep uncomfortably loud and turned the sound off. The company had her try carrying the device on a shoulder strap, which bothered her, or in a little holster on a belt, which worked better. She was told to keep a diary, noting every time she experienced a seizure.

While Leggett acclimated herself to the device, the device was, in effect, acclimatizing itself to her. The electrical signals detected by the apparatus in her head were transmitted to a lab, where a cluster of computers started to read the patterns of her neural activity, constructing an algorithm tailored to her needs.

Initially, the readings recorded by NeuroVista patients' devices were so strange—unlike either normal brain activity or the patterns that were typical of epilepsy—that the trial was almost abandoned. Later, the researchers realized that the brain was simply reacting to having been tampered with—the electrical equivalent of a postoperative wound. This disturbance settled down after a couple of months, and then the system's learning began. Once the device had recorded perhaps half a dozen of Leggett's typical seizures, the researchers were able to fine-tune the algorithm to the unique electrical signatures of her brain, readying the interface to move from observation to prediction.

The first time the device sent an alert, Leggett was at the hairdresser, a couple of blocks from her home. The external unit displayed a white light, and then a red one. She still remembers the shock of it—the strangeness of having a machine communicate with her and advise her what was about to happen in her head. She'd been told that the device would be able to warn her about fifteen minutes before a seizure hit. This gave her time to leave the hairdresser and get safely into bed at home.

Scientifically, the NeuroVista trial was a success, validating its underlying concept and generating a wealth of useful data. It was a success for Leggett, too, but in a way that was deeper and more complex than either she or the researchers had anticipated. The goal had been simple: to improve her life by giving her more control over her condition. The effect, though, had been to make Leggett feel like an entirely new person. She had never had a self that she could trust before. When I talked to her, she spoke of the device as if it were a partner. “We were calibrated together,” she said. “We became one.”

It is almost a quarter of a century since the F.D.A. first approved the use of a deep-brain-stimulation device—to treat essential tremor and advanced Parkinson’s disease. Today, at least two hundred thousand people worldwide, suffering from a wide range of conditions, live with a neural implant of some kind. In recent years, Mark Zuckerberg, Elon Musk, and Bryan Johnson, the founder of the payment-processing company Braintree, all announced neurotechnology projects for restoring or even enhancing human abilities. As we enter this new era of extra-human intelligence, it’s becoming apparent that many people develop an intense relationship with their device, often with profound effects on their sense of identity. These effects, though still little studied, are emerging as crucial to a treatment’s success.

The human brain is a small electrical device of super-galactic complexity. It contains an estimated hundred billion neurons, with many more links between them than there are stars in the Milky Way. Each neuron works by passing an electrical charge along its length, causing neurotransmitters to leap to the next neuron, which ignites in turn, usually in concert with many thousands of others. Somehow, human intelligence emerges from this constant, thrilling choreography. How it happens remains an almost total mystery, but it has become clear that neural technologies will be able to synch with the brain only if they learn the steps of this dance.

For three years after her operation, Leggett lived happily with her device. But in 2013 her neurologist gave her some bad news. NeuroVista had run out of funding and ceased operations. Leggett’s neural device would have to come out.

In January, 2020, toward the end of the Australian summer, I drove fifty kilometres along the Riddoch Highway, past pine plantations and remote estates, to the small town of Penola, South Australia. It was a hot, dry day, but though fires were burning in most of the country they hadn’t reached here. Rita Leggett lives at the edge of town in a pretty Colonial-style house. Behind it, a gnarled gum tree more than a hundred years old spreads its branches over the old iron tracks of a disused railway.

Now in her late fifties, Leggett wore her long hair in a dancer’s bun. She was animated, swinging between goofy jokes and an arresting sincerity that seemed born of a lot of suffering. As she told me her story, I noticed her long fingers continually in motion, twining and clasping and pointing while she spoke. Born in 1961, the first of six sisters, she grew up in a small town in Victoria. Her father left the family when she was nine, and she remembers her mother driving her back and forth on many long trips to a children’s hospital in Melbourne. At school, Leggett had no friends and was often bullied because of her epilepsy. She never understood why people were mean to her because of something that she could not control. She wanted to hide all the time.

When she was twelve, a miracle occurred: the seizures stopped, and her doctors, after monitoring her for a while, told her that she no longer needed to come to the hospital. “I was normal,” she recalled. “Wow!” She left school at sixteen and soon got a job at Target, saving her money to buy a car. But one day, when she was eighteen, she woke up confused and sore on a stretcher in the locker room at work, having no idea how she had got there. The seizures were back, and, from then on, she had one every week or so. They would last only a few minutes, but she never knew when they would come. She couldn’t drive or swim. She saw many different neurologists and tried many medications, none of which worked.

I asked Leggett to describe what it was like to have a seizure. She didn’t know. When one took hold, she was ripped out of her consciousness; she wasn’t there. Afterward, there was a terrible sense of having been absent. She would feel mortified in front of anyone who had witnessed the seizure and alarmed as she took stock of the injuries that she often suffered. Even worse, she said,

was that epilepsy stole her memories. Every time she had a seizure and then returned, she seemed to have left some of her memories behind her.

Many individuals with epilepsy feel profoundly misunderstood. The condition still carries a significant stigma. Something about it—the way it comes from nowhere and hijacks the self—terrifies people. Although epilepsy affects more than fifty million people worldwide, some fifteen million of whom do not respond to medication, epilepsy research struggles to obtain funding. In the United States, multiple sclerosis, which affects an eighth of the number of people that epilepsy does, nonetheless attracts roughly five times more research money per patient from the N.I.H. Even now, epileptic seizures are not fully understood. Leggett's neurologist, Terry O'Brien, told me of a recent four-day symposium he'd attended devoted to defining a seizure. Specialists know one when they see one, he said, but at the end of the symposium nobody had come up with a unifying description. At the most basic level, he said, a seizure is a rogue electrical discharge, an oscillation that moves in time and space, a bit like a tornado. Understanding isn't helped by the fact that epilepsy is not a single disease, but rather the brain's response to a variety of pathologies. Consequently, people with epilepsy often struggle with other conditions. Leggett had severe migraines and suffered from depression. The suicide rate for people with epilepsy is between two and three times higher than it is in the rest of the population.

For neurologists, predicting seizures has long been an elusive goal. They occur once a year for some people, many times a day for others, and it's common for sufferers to be unable to say whether they've had one or not. Before the NeuroVista trial, there was no consensus that prediction was even possible. Yet the new device was remarkably effective for three of the ten patients who completed the trial, and Leggett was one of them. During the years she had it, she said, the device "told me what I needed to know, and it did that well." If the warning light came on, she took anti-seizure medication; the algorithm's predictive power was such that there was enough time for the medication to be absorbed. As a result, she didn't have seizures.

When I met Leggett, she had been without the NeuroVista brain-computer interface for six years, but, as soon as I began asking how she felt about it, she looked out the window and started to weep. "I miss my device," she said. Leggett felt grateful that everyone involved was sympathetic to her plight. They let her keep the implant as long as possible. But the demise of NeuroVista—after spending seventy million dollars to develop the technology and conduct the trial, it struggled to find further investors—made removal inevitable. If the battery ran out, or a lead broke, or the site of implantation became infected, the company would no longer be there to provide support. She remembered a solemn drive to Melbourne for the surgery, and then coming back home without the device. It felt as if she had left a part of herself behind.

In 2015, two years after Leggett's brain-computer interface was removed, she heard from a man named Frederic Gilbert. He was a philosopher at the University of Tasmania specializing in applied ethics. "He rang all the way from Tasmania," Leggett recalled. "I can't remember how he worded it, but I was so willing to talk to him about it, because, you know, no one else had asked." There had been no counselling after the trial ended, and Leggett had never spoken with the other patients, but Gilbert had managed to track some of them down; Leggett was the sixth and last he reached. He went to visit and asked her questions no one else had about her feelings toward the device and its removal. He had a French-Canadian accent, which she liked. "He's not bad-looking, either," she said.

Gilbert followed a standard series of questions in his interviews, but at some point that afternoon he abandoned the script. He hadn't met anyone who spoke so revealingly about the subjective experience of merging with a brain-computer interface. "With the device, I found myself," Leggett told him. "The device became me." He kept asking her to tell him more. What did she mean, that she found herself and that it became her? When she expressed frustration with the way it all had ended, Gilbert wanted to dig into that experience. His questions were straightforward, but he could sense that for her they were a release and a revelation.

Gilbert thought that neurotechnology was destined to be so integral to our lives that it urgently needed to be scrutinized and regulated. For four years, he had been assembling a unique body of evidence in support of his view, by finding people with brain implants and learning about their experiences. He believed that what Leggett had undergone was more than the removal of a device. When the device and Leggett began to work together, a new person emerged—a de-novo identity, a symbiosis of machine and mind. Gilbert likened the situation to the film "Blade Runner," in which humanlike androids develop a sense of self and run away from their creators.

The University of Tasmania, where Gilbert has worked since 2010, is in Hobart, in the foothills of the Wellington mountain range, and it overlooks the vast River Derwent. When I visited him there, it was an atypically hot day, and walking up a steep hill to his car felt like climbing a ladder. Gilbert, who is in his forties and—unusual for a philosopher—a former professional football player, didn't pause for breath. He hikes as often as he can in the forests nearby, some of the wildest in the world, and his boss later told me that he is the only person she knows of who achieved a personal best on Tasmania's South Coast Track, a six-day mountain trek through wilderness, by reducing the amount of water that he carried.

Gilbert grew up in an enormous extended family on a farm outside of Quebec City. He did chores on the farm and spent hours playing in nearby forests with his siblings and his many cousins. Gilbert was on a football team and was an especially fast runner. When he was nineteen, an American-football team in France, the Giants de St. Étienne, offered him a place. He travelled with them in Europe, and after a year he returned to Quebec to play college football, but he overtrained and injured himself. When you build your identity in one context, he told me, losing your ability to be useful in that context ruptures your identity. "You feel useless, futile," he said. He decided that he needed a break from himself.

Gilbert moved to Switzerland and enrolled at the University of Geneva, studying philosophy. He found that philosophical concepts gripped him most when they had tangible importance in people's lives. At the time, cloning was a hot topic, and Gilbert wrote his master's thesis on it. For him, the assumption that cloning could perfectly reproduce an individual made no sense, given that none of us is the same person we were five or ten years ago. Progressing to his Ph.D., he studied free will and began hanging out with scientists at the university's Frontiers in Genetics lab. This made him think about determinism in a scientific way. If there was such a thing as free will, he decided, it had to be biological.

That was in the early two-thousands, around the time that the F.D.A. extended its approval of deep-brain stimulation as a general treatment for Parkinson's. Research into brain-computer interfaces, much of it by the Department of Defense, was advancing rapidly. The field had fascinating implications for Gilbert's work on free will. Suppose that someone whose brain was artificially stimulated committed a crime: were they responsible for their actions?

For the great majority of patients, deep-brain stimulation was beneficial and life-changing, but there were occasional reports of strange behavioral reactions, such as hypomania and hypersexuality. Then, in 2006, a French team published a study about the unexpected consequences of otherwise successful implantations. Two years after a brain implant, sixty-five per cent of patients had a breakdown in their marriages or relationships, and sixty-four per cent wanted to leave their careers. Their intellect and their levels of anxiety and depression were the same as before, or, in the case of anxiety, had even improved, but they seemed to experience a fundamental estrangement from themselves. One felt like an electronic doll. Another said he felt like RoboCop, under remote control.

Gilbert describes himself as “an applied eliminativist.” He doesn’t believe in a soul, or a mind, at least as we normally think of them, and he strongly questions whether there is a thing you could call a self. He suspected that people whose marriages broke down had built their identities and their relationships around their pathologies. When those were removed, the relationships no longer worked. Gilbert began to interview patients. He used standardized questionnaires, a procedure that is methodologically vital for making dependable comparisons, but soon he came to feel that something about this unprecedented human experience was lost when individual stories were left out. The effects he was studying were inextricable from his subjects’ identities, even though those identities changed.

Many people reported that the person they were after treatment was entirely different from the one they’d been when they had only dreamed of relief from their symptoms. Some experienced an uncharacteristic buoyancy and confidence. One woman felt fifteen years younger and tried to lift a pool table, rupturing a disk in her back. One man noticed that his newfound confidence was making life hard for his wife; he was too “full-on.” Another woman became impulsive, walking ten kilometres to a psychologist’s appointment nine days after her surgery. She was unrecognizable to her family. They told her that they grieved for the old her.

Not everyone in the NeuroVista trial loved their device the way Rita Leggett did. South of Melbourne, I met Hannah Galvin, a quirky, ethereal woman in her early thirties, who told me in looping, heartfelt narratives how she came to hate hers. As a child, she told me, she had lived for dance, but when she was sixteen she had her first grand-mal seizure, shortly before an important performance. She was shattered to learn that she wouldn’t be allowed to perform.

For years, Galvin resisted her diagnosis. She told friends that if she had a seizure they should make a joke of it. She continued going to auditions, even though she would have small seizures throughout them. As far as she was concerned, the seizures weren’t an aspect of her life but rather a quick step out of it. “I’m gone and I come back and that’s that. And then my life continues,” she explained. “I didn’t want to know anything else about it.” Nonetheless, she noticed other changes. She’d always been good at math but, once her epilepsy began, that part of her just seemed to vanish. She had always been happy, too, but three years into her epilepsy, struggling to get the right dose of medication, she became suicidally depressed.

When she was twenty-two, she joined the NeuroVista trial. Her antipathy to her device was almost instant. It felt as if there were someone inside her head, but it wasn’t her. She hated the telemetry unit embedded in her chest—“the tit antenna,” she called it. She hated having to carry the external unit around, and never knew where to put it. Worst of all, the unit’s warning light flashed at her all the time. It wasn’t faulty; it was correctly predicting as many as a hundred tiny seizures a day. Neither she nor her doctors had had any idea that she was so affected. She even had seizures when she was asleep.

Galvin had found it hard enough to accept that she had epilepsy to begin with. Now this gadget constantly harangued her, and she sank again into depression. She recalled being interviewed by a journalist, who asked how she felt about joining the trial. She said that her life was fine. But it wasn’t. “I was too young to tell the truth,” she said to me. Galvin complained about the device but didn’t feel that anyone at NeuroVista took her seriously. When it was finally removed, she was enormously relieved.

As different as Galvin’s and Leggett’s reactions to the device were, they shared a sense that experiences like theirs are something that the field needs to learn from. Gilbert, too, believes that patients’ perspectives are vital, and that we are only just starting to understand how a person’s selfhood can affect—and be affected by—an intelligent neural device. Observing a number of first-in-human trials, he has noticed that he sometimes stops hearing from patients for whom the results were poor. He knows of a number of patients who killed themselves after an implant.

Ethical issues are in constant danger of being overshadowed because of how rapidly technologies are developing. So far, the F.D.A. has approved deep-brain stimulation for a variety of conditions that affect movement, but Gilbert said that trials are under way

that will test intelligent neural devices on patients with dementia and psychiatric conditions including anorexia, schizophrenia, depression, obsessive-compulsive disorder, and Tourette's syndrome.

Gilbert believes that the medical-device industry has too much influence on how trials have been run. Most published papers don't mention ethics or risk, and, he said, because companies have no obligation to publish the outcomes of failed trials, the results over all appear to be ninety-nine per cent positive. Gilbert has been working on protocols to prevent harm: Neurosurgeons must declare financial interests. The risks described on consent forms need to be better articulated. Participants in early trials must understand that irreversible consequences of the trial might prevent them from receiving the better therapy they are helping to develop. All trials should express interest in the autonomy of a patient after implantation and after explantation. International research projects must also contend with national differences in ethical standards. A few years ago, Gilbert withdrew from a project with a Chinese team after learning that one of the researchers had previously carried out surgery on women with anorexia, resecting a part of their brains associated with pleasure.

Gilbert worries most about the coercion of vulnerable people. In 2013, a woman wrote to him saying that she had been implanted with a neural device as part of a trial that used deep-brain stimulation to treat depression. Launched in 2008 and known as the BROADEN trial (an acronym derived from the brain region it targeted), it was poorly managed and eventually shut down. The woman told Gilbert that, after her surgery, she had experienced a dramatic feeling of depersonalization and soon became suicidal. Her doctors, alarmed, wanted to remove her implant, but the woman was unwilling; she believed that she hadn't yet had a chance to experience all its potential benefits. Her doctors told her that she was not competent to make the decision, and yet the long e-mails she wrote to Gilbert seemed perfectly coherent and rational. In such a situation, Gilbert thought, the removal of the device was arguably a violation of human rights. After a year, the woman stopped writing to Gilbert. He looked for her online for years afterward but was never able to find her.

While Leggett still had her device, she tried online dating. She'd never done anything like that before. At the time, she was living in Victoria, but she met a man who was willing to drive hundreds of miles from his home, in South Australia, to spend time with her. They were both around fifty and soon reached a point at which they decided to close the previous chapters of their lives and start a new one together. They got married, and on the day she walked down the aisle she took her external processing unit off and put it aside. It didn't go with her dress, she said, and she had a feeling that she was going to be O.K.

When Leggett was told that she wouldn't be able to keep her device, her new husband sat with her and her neurologist and asked if there was anything he could do to prevent her having to give it up. When she returned to the hospital to have it removed, he was there with her.

Leggett's identity changed again once the device was gone. Now she knew great loss, but she also knew things that had been impossible to understand before the device. Like many people with epilepsy, she had often found herself fuzzy for a considerable amount of time after a seizure. That state made it very difficult to notice the signs that preceded seizures which could act as a natural warning light. These days, when she gets a funny, flip-floppy feeling inside, she takes anti-seizure medication. She's not always sure. Sometimes she gets her husband to weigh in. He says, "Go with your first instinct," and usually she takes a pill. She is now seizure-free.

"Losing it was terrible, but, looking back on it now, what I've gained from it is valuable," Leggett told me. "Would I have another one? Yes, I would love it." ♦

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Christine Kenneally, the author of “[The First Word](#)” and “[The Invisible History of the Human Race](#),” is at work on a new book, “[Ghosts of the Orphanage](#).”

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