

THE
MAN
WHO
WASN'T
THERE

INVESTIGATIONS INTO
THE STRANGE NEW SCIENCE
OF THE SELF

Anil Ananthaswamy

DUTTON
— est. 1852 —

paradoxically bereft of boundaries, leading to a feeling of transcendental oneness. Is this condition bringing us closer to the essence of the self—a self that maybe endures for just moments and is at the heart of the debate about whether there is or there isn't a self?

We conclude with a journey to Sarnath, India, where the Buddha, nearly 2,500 years ago, gave his first sermon. Buddhist ideas of no-self seem to resonate with what some modern philosophers are saying about the self—that it's illusory. But is it really? Does empirical evidence support the idea that the self is a made-up entity? Insights gleaned from the maladies of the self will help us make sense of age-old questions and maybe even ask a few of our own.



While visiting David Cohen in Paris, I asked him about May, his fifteen-year-old Cotard's syndrome patient. "Who is it that is saying she doesn't exist?"

"This is the mystery of psychiatry," Cohen said. "We always say that there is something . . . that can still relate to the real world, even in the most crazy state."

In Liège, Steven Laureys's PhD student Athena Demertzi, who helped Laureys scan and study Graham, told me something about Graham that also reminded me that despite his delusion of being brain dead, there was an essence that remained. Graham had just come out of the scanner when Demertzi asked him, "Are you OK?"

"I'm OK," replied Graham.

"Alive and kicking?" she asked.

"Kicking," said Graham, pointedly.

The self is both remarkably robust and frighteningly fragile. This book, I hope, brings to life this essential paradox of who we are.

2

THE UNMAKING OF YOUR STORY

MEMORIES, A PERSON, A NARRATIVE—
AND ITS UNRAVELING

Memory, connecting inconceivable mystery to inconceivable mystery, performs the impossible by the strength of her divine arms; holds together past and present,—beholding both,—existing in both . . . and gives continuity and dignity to human life. It holds us to our family, to our friends. Hereby a home is possible.

—Ralph Waldo Emerson

All those moments will be lost in time, like tears in rain.

—Replicant Roy Batty in *Blade Runner*

Allan, Michaele, and I are sitting in the living room of their home in California. Allan is settled into a large, high-backed, brown leather sofa, looking distinguished with his white beard and mustache and balding pate, and surprisingly dark eyebrows. At first glance I'm unable to tell anything's amiss. Michaele sits on a chair next to him. I

ask Allan if he has any brothers or sisters. He says no, and then corrects himself immediately. "Oh, I had a brother who was demented," he says.

"Retarded," Michaele gently corrects him.

"Retarded," Allan agrees. "No one knew he was retarded until he was [about] four. I was eighteen. I didn't understand a lot."

"But you were ten when he was four," Michaele says.

"OK," says Allan.

"Allan, do you remember much about your brother?" I ask.

"A sadness about him," says Allan. "Because he couldn't talk and stuff like that. I'd take him for a walk or something like that. He never said a word."

After a small pause, he adds, "I don't even know if he's still alive."

"No, honey, he died," says Michaele. "He died the year you and I met."

Allan and Michaele met nearly thirty years ago. Allan had been a philosophy professor at a community college, Michaele a forty-year-old working as a midwife, back at school after finding herself at a cusp in her life.

"Do you remember how he died?" asks Michaele.

"I thought he died in his sleep or something," says Allan.

Actually, Allan's brother had been hospitalized for a blood clot, and while at the hospital he fell out of an upper-floor window and died. At the time, thirty years ago, Allan had told Michaele that his brother, given his diminished mental capacities, would not have had the wherewithal to jump; he had probably wanted to get home and likely stepped out of the window thinking he was on the ground floor.

When Michaele reminds Allan of this during our conversation, he says, "Oh, that's something I wanted to forget, but no . . . fell out of the window . . ." He mumbles; his words meander.

"What did they say at the hospital?" asks Michaele.

"I was too sad and too young to take it in," says Allan.

Michaele turns to me and points out that Allan was fifty years old when his brother died.



On December 21, 1995, researchers in Germany found a blue cardboard file that had been missing for nearly ninety years. The file contained the case report for a patient named Auguste D, a fifty-one-year-old woman from Frankfurt. A handwritten note in the file, dated November 26, 1901, captured an exchange between Auguste and her doctor, Aloysius "Alois" Alzheimer, which the German researchers published in the journal *Lancet* in 1997 (with Auguste's answers italicized):

She sits on the bed with a helpless expression. What is your name? *Auguste*. Last name? *Auguste*. What is your husband's name? *Auguste, I think*. Your husband? *Ah, my husband*. She looks as if she didn't understand the question. Are you married? *To Auguste*. Mrs D? *Yes, yes, Auguste D*. How long have you been here? She seems to be trying to remember. *Three weeks*. What is this? I show her a pencil. *A pen*. A purse and key, diary, cigar are identified correctly. At lunch she eats cauliflower and pork. Asked what she is eating she answers *spinach*. When she was chewing meat and asked what she was doing, she answered *potatoes* and then *horseradish*. When objects are shown to her, she does not remember after a short time which objects have been shown. In between she always speaks about twins.

Three days later, Alzheimer made further notes:

On what street do you live? *I can tell you, I must wait a bit.* What did I ask you? *Well, this is Frankfurt am Main.* On what street do you live? *Waldemarstreet, not, no. . . .* When did you marry? *I don't know at present. The woman lives on the same floor.* Which woman? *The woman where we are living.* The patient calls *Mrs G, Mrs G, here a step deeper, she lives. . . .* I show her a key, a pencil and a book and she names them correctly. What did I show you? *I don't know I don't know.* It's difficult isn't it? *So anxious, so anxious.* I show her 3 fingers; how many fingers? 3. Are you still anxious *Yes.* How many fingers did I show you? *Well this is Frankfurt am Main.*

Auguste died on April 8, 1906. By then, Alzheimer had moved from Frankfurt to the Royal Psychiatric Clinic in Munich, so he had Auguste's brain sent there, where he "sampled thin slices of this brain tissue, [and] stained them with silver salts." After affixing these slices between glass slides, "Alzheimer put down his habitual cigar, removed his pince-nez, and peered into his state-of-the-art Zeiss microscope. Then, at a magnification of several hundred times, he finally saw her disease."

Summer passed and in the fall, on November 4, Alzheimer presented his findings at the 37th Conference of South-West German Psychiatrists in Tübingen. Auguste, he said, had "progressive cognitive impairment, focal symptoms, hallucinations, delusions, and psychosocial incompetence." More to the point, the cells in her cerebral cortex showed weird abnormalities.

The following year, Alzheimer published a paper called "A Characteristic Serious Disease of the Cerebral Cortex," in which he detailed the abnormalities. One was found inside neurons: "In the centre of an

otherwise almost normal cell there stands out one or several fibrils due to their characteristic thickness and peculiar impregnability." Alzheimer also identified "miliary foci," places between cells where he saw aggregates of a strange substance.

It was a new form of dementia. In 1910, Emil Kraepelin, the director of the Royal Psychiatric Clinic, coined the term "Alzheimer's disease" for such strange cases of dementia, and wrote, "The clinical interpretation of this Alzheimer's disease is still unclear. Although the anatomical findings suggest that we are dealing with a particularly serious form of senile dementia, the fact is that this disease sometimes starts as early as in the late forties."

The abnormalities Alzheimer had identified in Auguste D's brain were what are now called neurofibrillary tangles and plaques of beta-amyloid protein. While neuroscientists are still debating which comes first—the neurofibrillary tangles or the beta-amyloid plaques (with some wondering whether there are precursors to these neuropathologies)—it's clear that these aberrant proteins are involved in the ruthless progression of the disease.

If Auguste D had come to see a neurologist today, she would have been diagnosed with Alzheimer's disease.



Michaele had been working as a lay midwife, helping with home births, in the early 1980s when midwifery was not strictly regulated in California. But with the legal issues surrounding her work becoming more challenging, Michaele decided to go back to nursing school. As part of her studies, she took a class in philosophy being taught by a charismatic fifty-year-old professor. He sauntered into the classroom wearing a leather jacket and large horn-rimmed tortoiseshell glasses, with

white hair and a beard, and discussed philosophy and governments with dramatic flair. "I believe governments should be run by Romanian gypsies and ballet dancers, instead of dictators and greedy politicians," Michaele recalled him saying. She was mesmerized.

Soon, they began seeing each other ("lots of notes on the door and clandestine meetings after class," said Michaele). He was in the process of separating from his wife, and drinking a lot; she too was struggling with a bad marriage, which had started disintegrating around the time she went back to school. They both had children. But none of that stopped them as they tumbled into love.

The day I met Allan, I asked him about what Michaele had said, about being blown away by him. "Well, we were both blown the same way," he said, his voice surprisingly firm and confident. "It was . . ." He then struggled to find the right word. "Things that swirl up in the air." Tornado, I offered as a suggestion. "Tornado," he agreed.

Eventually, they bought a house together (the one I visited), got married, traveled together, often to Europe, and remade their lives around each other. Michaele recalled that one of her sons had pointed this out in his toast at their wedding: "It's always been my mom and Allan against the world . . . They have made it work . . . They have made a life for themselves, despite the challenges."

Nothing about Allan's personality had prepared Michaele for what was to come. "When it started happening, I never imagined, *never*, that he'd ever be a person with dementia," she said.

The first hints came in spring 2003. Michaele and Allan took a weekend break and went up the Eel River in Northern California, and stayed at the Benbow Historic Inn in Garberville. When they came back home on Monday, they found their answering machine overflowing with messages from Allan's department secretary and students.

Allan had completely forgotten that he had scheduled a final exam that day. It was the first serious indication that something was wrong with his memory.

In September of that year, they went to Europe for a vacation, and Michaele found Allan unable to cope with anything new. He constantly got lost, could not navigate through the French countryside, would put his ATM card into a movie-rental machine, and even had trouble packing his own suitcase.

Back in California, Allan began showing further signs of dementia. He'd forget how to get to his daughter's home, which was not too far from where they lived. There were other things that seemed amiss. "I'd come home and find him cleaning the hot tub with the circuit breaker still on, which was very dangerous. You can get an electric shock," Michaele told me. "And when I'd tell him to go turn off the circuit breaker, he would go looking in the garage, when it was on the other side of the house."

It took a year for them to see a neurologist. Allan failed some standard tests (counting backward from 100 in decrements of 7, for example, which requires the patient to concentrate and is a test for declining cognitive ability), but he still did reasonably well, which the neurologist attributed to Allan's high intelligence. The MRI suggested some small occlusions of blood vessels. The neurologist diagnosed Allan as being in the early stages of vascular dementia (the decline of cognitive processes due to impaired blood flow in the brain). A few years later, Allan's diagnosis was changed to Alzheimer's disease.

Meanwhile, Allan's personality was changing too. During their entire love affair and married life prior to his diagnosis, Allan had been a kind, sweet man. He and Michaele would have the usual arguments that all couples do, but they would resolve them almost imme-

diately by talking things through. "He was very present," Michaele told me.

Not so once Alzheimer's set in. The slightest argument and Allan would storm out of the house, slamming the door behind him, and go "tearing off in his car." He also wrote notes incessantly—an old habit that now provided glimpses into Allan's morphing personality. "Some of them were really mean," said Michaele. "If I had called him on something, he'd go write a nasty note, 'Bitch-fest number 5.'" Or simply, "Bitch, bitch, bitch . . ."

The notes also revealed his torment at having been diagnosed with dementia. Michaele recalled one note that said "Get me out of this fucking hole." Allan read all the books he could find on the disease, and even read *Final Exit*, a book that offered those suffering from terminal illnesses a way out via assisted suicide (he kept the book on the end table near his bed). He told Michaele, "I don't want to ever end up in diapers. I don't want to ever end up in a nursing home. You have to take me down to the Bay and push me off the pier." Michaele knew she would do no such thing. "I couldn't do that, Allan, I would go to jail," she recalled telling him. "I could be charged with murder. If you want to do it, I totally get it, but you are going to have to do it. I'd support you, but I won't help you, at least not do it for you."

In the face of Alzheimer's, Allan's sharp intelligence and his cerebral personality became a double-edged sword. "The thought of him losing his brain was the most horrific thing because that's the thing he valued the most: his brain, his intelligence," Michaele said.



"Alzheimer's disease robs you of *who you are*. I don't think there's any greater fear for a person than to think I've lived my whole life accumu-

lating all these memories, all these value systems, all of this place and my family and a society and here's a disease that's just going to come in and every single day just rip out the connections, just tear out the seams that actually define *who I am as a person* [italics mine]," says Rudolph Tanzi, professor of neurology at Harvard University, eloquently articulating the scary eventual outcome of Alzheimer's disease in the PBS documentary *The Forgetting: A Portrait of Alzheimer's*.

Talk at any length to caregivers like Michaele about their loved ones, and you cannot escape the conclusion that the disease destroys the very essence of one's being. At least, that's the perception from the outside.

"It's very hard," said Clare, a sixty-year-old woman of Norwegian descent living in California. "Somebody that you grew up with disappears before your eyes." Clare's ninety-year-old father is in the late stages of Alzheimer's and the family has moved him into an assisted-living center. Clare visits him often, as does her mother. "He physically looks the same but when you look in his eyes, there's nothing there," Clare told me, her voice dropping to a whisper. "There's really nothing there."

The vast medical literature will concur with Clare. Consider the phrases used to describe Alzheimer's impact: "a steady erosion of selfhood," "unbecoming" a self, "drifting towards the threshold of unbeing," and even "the complete loss of self."

Still, there are scientists, particularly social scientists, who are challenging such notions. If Alzheimer's erodes the self, does the erosion go all the way until, truly, nothing's left? We know that Alzheimer's disease destroys cognitive abilities, to the point where the person is unable to take care of himself or herself, where putting on one's pants or brushing one's teeth becomes impossible, to say nothing of

the ability to recall the date and time, or recognize family members. But given that the person's sensory and motor functions are spared, does anything remain of one's self when cognition and its attendant abilities are wiped out?

Answering such questions requires us to return to what philosophers, scientists, and social scientists think the self is. Some argue that the self is fundamentally a narrative construct. It's true that one of the key aspects of the self is the narrative—the story or stories we tell others and indeed ourselves about who we are; these stories depend on remembering and imagining. “Individuals construct private and personal stories linking diverse events of their lives into unified and understandable wholes. These are stories about the self. They are the basis of personal identity and self-understanding and they provide answers to the question ‘Who am I?’” wrote psychologist Donald Polkinghorne.

It's not hard to accept that our various narratives are part of the self, but is the self constituted solely of narratives, or does it have other aspects that exist before narratives are formed? Some philosophers argue that narratives constitute the self in its entirety—nothing's left once the narrative goes. To them, “the self is ultimately nothing but a dense constellation of interwoven narratives, an emergent entity that gradually unfurls from (and is thus constituted by) the stories we tell and have told about us.”

This notion of narrative-as-selfhood even places the cognitive act of constructing narratives at the heart of being a self. But the experiences of people suffering from Alzheimer's pose at least two challenges to this view of the self.

One is the idea that cognition—and its role in creating narratives—is central to the self. Pia Kontos, of the University of Toronto, has been

observing people with dementia for more than a decade and takes issue with such a notion of the self. “There is something of who we are that exists separate and independent from cognition,” she told me.

She realizes that this claim is controversial. “It's a perspective that challenges the whole Western construction of selfhood, because central to [our understanding of selfhood] is rationality and independence and control. It sort of goes back to [Descartes], the split between mind and body. It's not just a split between mind and body, but it's a very particular notion of dualism, where the body is relegated to nothingness. It's just an empty shell, and really everything, in terms of sense of self and agency and intentionality, is attributed to the mind.” Kontos wants to bring the body into the discourse on selfhood, agency, and even memory.

So, even if we were to view selfhood as a narrative, the narrative would not be solely the purview of cognition; the body has its say.

And Alzheimer's disease defies the narrative-only view of the self in yet another way. It challenges those who argue that the self is best understood as constituted of *and by* narratives—and that there is nothing else besides these narratives. While the disease does destroy one's ability to have and tell a coherent story, what remains once this narrative self disintegrates is less clear. “It is by no means obvious that . . . any experience that remains is merely an anonymous and un-owned experiential episode, so that the ‘subject’ no longer feels pain or discomfort as his or her own,” writes philosopher Dan Zahavi. Understanding what might be left behind once the narrative self is gone could point us to the brain processes that beget the self.

Zahavi, for example, argues that the self, before it becomes a full-fledged narrative, must be something minimal, something that is capable of being the subject of an experience in any given moment.

So, despite its relentless degradations, Alzheimer's disease is allowing us to examine the self in ways that are more layered and more nuanced. This emerging picture of the self will tell us what it means to be a person with end-stage Alzheimer's and influence how we take care of those people.



Around the time Clare's father was diagnosed with Alzheimer's disease, he walked over to the local police station—in a small town an hour's drive north of Sacramento, California—and handed the police a gun that he owned. "I got rid of the pistol because I'm afraid I'm going to use it on myself," he told Clare. Soon after, Clare's parents sold their farm and moved to a much smaller house. The farm had become too much to manage.

Clare's parents came to America from Europe when Clare was four years old. Her father was a scientist who worked for a major corporation, was extremely successful, retired early, bought his family a farm—something Clare's mother had always wanted—and settled into an altogether different kind of life amid farmers, ranchers, and cattlemen's associations. It was during one of her visits to the farm that Clare noticed something was amiss. They were having a barbecue. Her father, who always did the barbecuing, turned around to Clare and said, "I don't know quite how to do this." Clare thought he was kidding; surely he knew how to barbecue? "Oh, come on, you know what you are doing," she said. "No, Clare, I'm not [kidding]. Something is wrong," he said. It felt wrong to him in the same way that it felt wrong when he couldn't think of certain words.

He had told Clare earlier that, at times, he had to search for the right words for something he had in mind (the way Allan had strug-

gled for the word "tornado"). Clare realized that this was a big deal for her father. "Perhaps everybody says this about their father, and especially their father with Alzheimer's disease, but in my case, I really think it was true," Clare told me. "He was an extraordinarily intelligent man. He spoke seven languages and he was quite good at them. And so words were kind of easy for him and when they started disappearing, he was concerned."

Such concerns grew. Clare remembered one key moment with her father that made it clear he was getting worse. And it centered on something he used to love: sailing. He was an accomplished sailor, who could navigate the seas at night by the stars and often would charter a large sailboat, invite friends, and sail around the Great Lakes, even the Caribbean. Once, in the 1980s, they were sailing off St. Barths (with an "interesting" group of sailors that included two Argentinians, recalled Clare; she was the only woman on board), when a massive storm hit the region. Clare's response was "Let's get out of here," but her dad (the captain) wasn't bailing out just yet. The dinghy attached to their sailboat was being whipped around by the wind and the waves and taking on water, becoming a drag on their sailboat. Everyone wanted to cut the dinghy free, but Clare's father refused to do so. Through it all he remained keenly aware of his boat; even while asleep in the middle of the night, having dropped anchor, many a time he'd know that the anchor hadn't quite grabbed. He'd make Clare get up and together they would reset the anchor. He saw them through the storm.

More than a decade later, Clare and her cousin decided to take her dad on a sailing trip. By this point, they knew something wasn't quite right with him. So this time, Clare's cousin acted as captain and Clare the first mate. Her dad was just a fellow sailor. "He knew his way

around the boat, and he could sail, but he also was quite happy that he wasn't in charge. He wasn't offended or outraged by that," recalled Clare. But there were indications of his difficulties. Sometimes, when Clare and her cousin were doing a tough maneuver, her dad would stand up and risk getting hit by the swinging boom. She would have to shout out, asking him to sit down. And yet when they set a course and put him behind the wheel, he could still maintain a compass bearing, trimming the sails as necessary.

Then suddenly, out of the blue, he'd say, "What day is it? What day is it? What day is it?"

A few years later (and after he had been diagnosed with Alzheimer's), Clare and her dad were walking through the center of a small coastal town and saw a church sale. There was a model sailboat on display. Clare's father picked it up. "He looked at it, and he looked at it. He knew that he was interested in it, but I also had the sense he wasn't really sure why he was interested in it," Clare told me. "None of it was verbalized. It was in the way he was holding his body. The look on his face, which was sort of looking, but yet there was no comprehension that I could see going on." The once-accomplished sailor no longer remembered a sailboat.

She knew then that her dad's Alzheimer's had moved way beyond just short-term memory lapses.



Much of what we know about memory and the brain structures that support it comes from the study of one unusual man, who, for better or for worse, lived *in the moment* from the age of twenty-seven. Students of psychology and neuroscience know him as patient H. M.; he was Henry G. Molaison, born in 1926. Henry began having epileptic

seizures when he was ten years old, possibly because of a minor head injury a few years earlier (but the causation was unclear; there might have been a genetic predisposition, given that Henry's cousins on his father's side also suffered from epilepsy). The seizures got progressively worse. Anticonvulsant drugs had no effect, so much so that Henry, a high-school graduate, barely managed to continue at his job on a typewriter assembly line. Eventually, in 1953, when Henry was twenty-seven years old, the neurosurgeon William Beecher Scoville of Hartford Hospital in Connecticut decided on a risky experimental surgery to treat Henry's epilepsy.

Scoville drilled two holes just above Henry's eye sockets, into which he inserted flat brain spatulas—a neurosurgeon's version of the tongue depressor—parting the frontal and temporal lobes in the two brain hemispheres. This gave him access to brain structures of the medial temporal lobe, such as the amygdala and hippocampus. He then sucked out a chunk of normal brain tissue, including much of the amygdala and hippocampus. The effect this surgery had on Henry, his name now anonymized to H. M. in the academic literature, is neuroscience lore.

H. M. continued to take anticonvulsant medication, and his grand mal seizures dropped dramatically in intensity and frequency (from once a week to once a year). But something far more intriguing happened to his memory. He "could no longer recognize the hospital staff nor find his way to the bathroom, and he seemed to recall nothing of the day-to-day events of his hospital life." In a paper published in 1957, Scoville and a psychologist at the Montreal Neurological Institute, Brenda Milner, wrote about H. M.'s psychological examination: "This was performed on April 26, 1955. The memory defect was immediately apparent. The patient gave the date as March, 1953, and his age

as 27. Just before coming into the examining room he had been talking to Dr. Karl Pribram, yet he had no recollection of this at all and denied that anyone had spoken to him. In conversation, he reverted constantly to boyhood events and seemed scarcely to realize that he had had an operation."

H. M. continued to live a life lacking in new memories (a condition called anterograde amnesia), and there was also a limit to what he could recollect about his past. Milner continued to study H. M., a baton she would pass on to her student Suzanne Corkin. In 1984, Corkin wrote:

A striking feature of H.M. is the stability of his symptoms during the 31 postoperative years. He still exhibits a profound anterograde amnesia, and does not know where he lives, who cares for him, or what he ate at his last meal. His guesses as to the current year may be off by as much as 43 years, and, when he does not stop to calculate it, he estimates his age to be 10 to 26 years less than it is. In 1982, he did not recognize a picture of himself that had been taken on his 40th birthday in 1966. Nevertheless, he has islands of remembering, such as knowing that an astronaut is someone who travels in outer space, that a public figure named Kennedy was assassinated, and that rock music is "that new kind of music we have."

H. M.'s condition highlighted the different kinds of memory we possess, some of which were intact in him, while others had been obliterated. For starters, his short-term working memory was fine; he could retain a handful of numbers for tens of seconds. But surgery had scarred some forms of H. M.'s long-term memory.

His semantic memory—the ability to remember facts and concepts—was largely intact, but only for things that he had experienced before his surgery. Meanwhile, his episodic memory, which is the memory of an episode of experience and is linked to place and time, was ruined even for his pre-surgery days. Semantic and episodic memories are forms of long-term memory called declarative or explicit memory, which requires us to consciously access information. H. M.'s anterograde amnesia was so complete that he had no declarative memory for anything that happened after his surgery (though he did manage to remember the floor plan of the house he moved into after his surgery, and lived in from 1958 to 1974; gradual accumulation of knowledge over the years, aided no doubt by the fact that he physically inhabited and moved about in the same space for years, had somehow helped H. M. form a memory of where he lived—tantalizing evidence for the body's place in forming the self in concert with the brain).

The other broad category of long-term memory is called implicit, nondeclarative, or procedural memory. This is memory that does not require conscious access. Think about knowing how to ride a bicycle. It's memory that we access unconsciously. It was Milner's classic study of H. M., published in 1962, that showed us that distinct brain structures are involved in these various types of memory. In this study, H. M. was shown two star-shaped patterns, one inside the other. He was asked to replicate the pattern by drawing between the lines of the outer and inner patterns. To complicate things further, H. M. had to draw while looking at the reflection of his hand, the pencil, and the patterns in a mirror. Amazingly, H. M. got better and better at the task over three days—while retaining absolutely no memory of having done the task. It was clear that the surgery had not messed up his procedural memory. The question was: what exactly were the brain

structures that had been removed by the surgery? The papers written by Scoville after he performed H. M.'s surgery in 1953 were extremely illustrative for their time, but weren't the definitive word. In the 1990s and 2000s, H. M. underwent several brain scans, but they were, like all scans, noninvasive and hence somewhat limited in what they could precisely reveal about the excised brain regions. But more was revealed upon his death.

H. M. died on December 2, 2008. His body was transported to Mass General Hospital in Charlestown, Massachusetts, where neuroscientists spent nine hours imaging his brain. Later, a neuropathologist skillfully removed H. M.'s brain from his skull. All this led to a high-resolution 3-D model of H. M.'s brain, based on numerous fine-grained MRI scans. It was possible, finally, to dissect H. M.'s brain inside the computer. The new images confirmed what the earlier MRI scans had revealed: the back half of H. M.'s hippocampus in both hemispheres—which Scoville thought he had fully removed—was intact. But Scoville had removed something else in its entirety: the entorhinal cortex—the interface between the hippocampus and the neocortex (the part of the cortex that's unique to mammals). Alzheimer's disease begins in the entorhinal cortex and spreads. According to the literature, "It is the most heavily damaged of all cortical areas in Alzheimer's disease."

As for H. M., the "unforgettable amnesiac," he might have left no survivors, but he left behind an indelible mark on science. His profound amnesia sparked a debate over the question of whether he had a sense of self after his surgery. A similar question haunts those who are confronted with Alzheimer's disease today.



When most of us think of the sense of self, we are thinking of the stories in our heads about who we are. If you had to tell a story about yourself to someone else (or even to yourself) you may have to delve into your album of episodic memories that defines you. Call it the narrative self (aspects of this selfhood would not just be cognitive, but embodied, as Pia Kontos emphasizes). A narrative, by definition, is a sequence of episodes strung together. In some sense, that's what we are—a seemingly seamless narrative. As humans, we also have the ability to project this story into the future. Our narrative self, then, is not merely a remembered past but also an imagined future. Over the past decade, numerous studies have shown that the same brain networks that are responsible for remembering past events are also recruited when constructing future scenarios. For example, if you are a good sailor, as Clare's father was, you will use the same brain networks to remember last year's sailing trip as for imagining navigating the seas a few years hence. Key brain regions that form these networks include structures in the medial temporal lobe (the parts closer to the midline), including the hippocampus and the entorhinal cortex. It's these regions that are often first affected by Alzheimer's disease; it's here that the disease gains a foothold for its destructive march, eventually erasing a person's ability to construct a coherent narrative self.

In some Alzheimer's patients, this disruption of the narrative self manifests initially as anosognosia—not recognizing that you in fact have Alzheimer's. Joseph Babinski coined the term "anosognosia" in 1914 (in Greek, *agnosia* means lack of knowledge and *nosos* means disease) to describe an extremely odd behavior in some of his patients whose entire left sides were paralyzed. In his influential paper he wrote, "I want to draw attention to a mental disorder that I had the

opportunity to observe . . . which consists in the fact that patients seem unaware of or ignore the existence of their paralysis." Babinski's patients not only denied or were unaware of their paralysis, they also came up with rationalizations for their lack of knowledge. Babinski wrote about one patient, "If she was asked to move her right arm, she immediately executed the command. If she was asked to move the left one, she stayed still, silent, and behaved as if the question had been put to somebody else." A particularly severe form of anosognosia is seen in Anton's syndrome (named after neuroscientist Gabriel Anton, 1858–1933), in which patients who have become blind because of damage to both sides of their occipital lobes insist that they can see.

Anosognosia in Alzheimer's can range from mild unawareness to outright denial. Neuroscientist William Jagust, an expert on Alzheimer's disease at the Lawrence Berkeley National Laboratory, has encountered the entire gamut of reactions during his years of clinical practice. "The spouse brings the patient to the doctor, and the patient says, 'Nothing's wrong with me, you are crazy,' and they have fights and all that. . . . But more often, it's that the patient doesn't really notice [the disease], is unaware, rather than [in denial]," Jagust told me. Often, after intense meetings in which Jagust would tell the patient and the family about the diagnosis, the patient would soon forget the diagnosis. It's in the nature of the disease. "After you tell them they have Alzheimer's disease, they have to stop driving, they will want to drive. The family will say, 'The doctor said you have Alzheimer's disease' and they say, 'He didn't say that!'"

Allan, too, didn't want to give up driving. Before his formal diagnosis, he began having panic attacks while driving on freeways. So he stuck to local city driving, which still worried Michaele. She'd find unexplained dents on his car, even signs of being sideswiped by an-

other vehicle (Allan claimed the other driver was to blame, but Michaele suspected it was Allan's fault). Allan once tried to cover up an accident by spray-painting a scraped fender. A social worker at Allan's clinic warned Michaele that Allan could be sued if he got into an accident (by now he had been formally diagnosed). Allan's doctor alerted the Department of Motor Vehicles, and the DMV sent Allan a letter, asking him to come in and redo his written and road tests. "Damn it if he didn't pass the test," said Michaele. "I couldn't believe it." Eventually, to her relief, Allan's car was stolen and trashed by thieves. For Allan, it was a body blow. "He was very sad. He wrote a whole lament to his Honda on yellow paper, on just how much it meant to him, how the loss of his autonomy was a tragedy, that he wasn't a whole person anymore," Michaele told me. "It's like his sense of self was eroding."

Allan's anosognosia was perhaps mild in comparison to the level of denial of those with paralysis. Nevertheless, Alzheimer's is allowing us to understand the neural mechanisms behind anosognosia and its relationship to the sense of self. It's these mechanisms that Giovanna Zamboni, a neurologist at Oxford University, is studying. In one of her studies, she found that Alzheimer's patients with anosognosia were far better at judging traits of a close friend, caregiver, or relative than they were at judging themselves. The tasks, which were done inside an fMRI scanner, revealed that the medial prefrontal cortex (MPFC) and the left anterior temporal lobe in Alzheimer's patients were less active during self-appraisal than during tasks that required the appraisal of others (normal controls and those with mild cognitive impairment showed no such difference).

The tests reveal that anosognosia in Alzheimer's is not just a problem of memory—it's also a problem of self. "It reflects a very selective

inability of updating the information regarding you, but not regarding others," Zamboni told me.

Robin Morris, a neuropsychologist at the Institute of Psychiatry at King's College London, would agree. Morris thinks anosognosia in Alzheimer's stems from a bigger problem than merely not remembering you have been diagnosed with the disease. We have, Morris argues, a special form of semantic memory that has to do with knowledge about ourselves—a self-representation system. This "personal database" is different from semantic knowledge about objects and facts about the world and other external things. "There is something particularly special about self-representation," Morris said when we met at his office in London. He hypothesized that in Alzheimer's, "people are not integrating new information into their self-representations."

According to Morris, this self-representation is essentially episodic memory that has somehow been turned into semantic memory about oneself—it's been semanticized, so to speak. Patient H. M. lends support to the idea that the essential meaning of our episodic memories is captured and stored in a semanticized form, separate from other episodic memories. When Suzanne Corkin asked H. M., "What is your favorite memory that you have of your mother?" he replied, "Well I, that she's just my mother." As Corkin found out, even though H. M. had memories of his childhood, "H.M. was unable to supply an episodic memory of his mother or his father—he could not narrate even one event that occurred at a specific time and place." Still, he had some sense of his pre-surgery self.

If our self-representation system is working well, then episodic memories are continually being converted to semantic memories, creating the gist of who we are. In Alzheimer's, the process seems to be disrupted. The brain's ability to continually update our self-

representation is compromised, evidenced by the anosognosia, but more profoundly by an alteration of one's narrative self. The formation of the narrative slows down, or even stops. The patients reach back into the depths of their memories to a time when the keystones of their narrative arcs were formed, when their enduring identities were forged. In what can only be called a cruel twist of fate, this aspect of our sense of self that lets us travel back and forth in time, remembering or creating identity—what philosophers call *autonoetic consciousness*—is among the last of our cognitive abilities to mature during childhood, but one of the first to begin crumbling under the assault of Alzheimer's.



The day I met and talked with Allan, he was surprisingly present and charming. Michaela was glad he was so—it was that time of day, she said, early afternoon, a small window of awareness before he would lapse into a state where he would be difficult, even unreachable.

"Is there anything about Alzheimer's that worries you going forward?" I asked Allan.

"No, I think I have given up forward," he said. "I'm seventy, seventy-one." (He was eighty-one when we spoke, seventy when he was diagnosed.) "It's been a good life. Things could be much worse. Solved problems of the world, have two children, now two grandchildren. That's good. Saw the world when I was in the Air Force." It was when he was stationed in Germany with the US Air Force that he saw the destruction wrought by the Second World War. He was deeply moved by a visit to the site of a concentration camp in Dachau, which cemented his evolving view that the world would be better off being run by gypsies and ballet dancers—his shorthand for "people with little

means and those with a love of the arts," said Michaele—than by dictators and politicians.

Michaele had pointed out—and I noticed it too—that Allan kept going back to his strongest memories: from his time spent in the Air Force to becoming a teacher of philosophy. There's a reason why he was doing this. It's a time when Allan was cementing his identity. "We think you incorporate those memories more powerfully into your sense of self, and you form richer, more enduring representations," Robin Morris told me. "Those basic building blocks—the essential concepts which define who you are—don't change over your lifetime, or they change more subtly."

End-stage Alzheimer's disease will get to those too, but for the time being, Allan had reserves that allowed him to remember back to when he was eighteen, when he got kicked out of school three times for smoking cigarettes. The school counselor suggested he join the Air Force, and Allan did. He was sent to a base near Munich, Germany, where he learned to be an airplane mechanic. He came back to San Francisco at the age of twenty-two and began working for United Airlines and attending community college. He wanted to become a radio broadcaster, but one of his teachers said he didn't have the voice to become a broadcaster, and encouraged him to take classes in philosophy. The advice turned out well—Allan loved philosophy, soon began teaching philosophy, and became a beloved teacher.

When I talked with Allan, he did not quite get the details or the sequence right (I could tell because Michaele had already filled me in).

For instance, when talking about the teacher who suggested he study philosophy, Allan said, "He was the one who said, 'Since you got kicked out . . . cigarettes, why don't you go join the Air Force.'" Actually, by the time he'd met the teacher, Allan had already been in the

Air Force, and the teacher had suggested that he take up philosophy classes.

If Michaele hadn't previously told me about Allan's past, I'd not have been able to temporally order his recollections. Toward the end of our meeting that day, Michaele left Allan and me alone to talk some more. I asked him again about his life. Here's a fragment of the conversation verbatim, when he talked of the Air Force again, after already having mentioned it a few times.

"We joined the Air Force here, and we continued to make up situations . . . you do. Everybody wanted to be an airplane flight, but then somebody said no, you have to have algebra. Some people said I don't have algebra. That's what I said. OK, we'll do something else. We got on the train in San Francisco, we went over up to Boston, got on a boat, a boat which is not much bigger than this room, and it was about twelve to fifteen people, and one of the finest things of all is that . . . many of those people . . . fallen sick. I'm one of the ones that didn't. We had to go out and puke. I had a picture of that once, yeah.

"Then we got off the train. About two and a half days to get to Munich. Munich is the center of Germany, that's where the place was. Making . . . Americans and Germans were together. We were there for . . . OK . . . two years . . . then we came back. I went to work for United Airlines, for years. Then everybody said, 'Why don't you go to college, because you are always reading books?' Which were detective books."

One vivid incident Allan mentioned several times during our conversation was the sight of farmers waving at the soldiers as their train sped through their fields. Allan would have been all of eighteen when he saw those farmers framed in the train window. But he couldn't correctly recollect whether he saw these farmers in Texas or in Ger-

many. While Alzheimer's disease hadn't yet destroyed Allan's most vivid memories, it had scrambled his narrative.



In his office in London, Robin Morris pointed out two key changes that are happening in patients with Alzheimer's. One, as we saw earlier, is that they are not able to acquire new knowledge about themselves, and so are unable to update their narrative self. The other is that there are probably brain structures responsible for supporting our self that are under attack by Alzheimer's, and so the person is falling back on the most resilient parts of his or her narrative. These resilient notions of oneself form during late adolescence and early adulthood—much like the version of himself that Allan was recalling during his rambling recollections.

Even healthy people, when they are asked to recall life events, will remember more events from when they were between the ages of ten and thirty, compared with their recall of events from before and after this time. Psychologists have a name for this: the reminiscence bump.

This bump has a significant influence on our self. Martin Conway, a psychologist at City University London, has worked extensively on memory and the self. Conway envisages an individual as having a hierarchy of goals. This hierarchy is broken up into smaller and smaller subgoals, becoming more and more specific the smaller the scope of the subgoal. For instance, you might have as a goal the idea of becoming an athlete—and smaller and smaller subgoals would involve more and more specific targets, all the way down to running five kilometers today. Conway defines a notion of the “working self” based on this hierarchy of goals, and the purpose of the working self is to reconcile a specific goal (becoming an athlete) to the current state (sitting on

the sofa, say) and ensure that the discrepancy between the two states is minimal (by making you get off that sofa and run). In other words, the working self regulates behavior.

Besides this working self, Conway identifies what he calls the conceptual self, an aspect of our self that contains notions of who we are, based on our interactions with others, including family, friends, society, and the broader culture.

The job of the working self, in Conway's model, is to regulate behavior and help in the formation and construction of memories that are consistent with the conceptual self and its goals. Consistency does not mean accuracy. For example, in the short term, it's important for me to remember whether I turned off the gas in the kitchen. Such short-term memory has to correspond to reality with high fidelity; otherwise there is a price to pay. However, it's impossible for the brain (at least in most of us who do not have photographic recall of every incident) to maintain such records ad infinitum. So, long-term memory is less constrained by fidelity and is more concerned with the need for “coherence”—that is, whatever enters long-term memory should not be dissonant with our conceptual self and goals, which are themselves influenced by existing long-term memories. As Conway puts it, the autobiographical knowledge in long-term memory “constrains what the self is, has been, and can be,” while the working self dictates what goes into long-term autobiographical memory and the ease with which it can be accessed. Stories influence who we are, what we do, what we can be: certain beginnings require certain endings; stories can become our reality.

According to Conway, the neural processes that implement the working self also ensure that long-term memories that are coherent with our goals and self-knowledge are more easily accessible than

those that are not. Crucially, memories of those experiences that were highly significant in meeting the goals of one's life seem to remain more strongly associated with the self and its history.

This brings us back to the reminiscence bump. "There is a critical period in late adolescence and early adulthood where you are defining your self-beliefs and self-concepts," Robin Morris told me. We form the core of our narrative self during this time.

So, the narrative self is influenced by highly significant events in one's life, and this self—or the memories associated with these events—then influences what you do next, and so dictates how your narrative grows. The self's need for coherence is paramount.

In patients with Alzheimer's, this narrative self is being disrupted on multiple fronts. To start with, the ability to form new episodic memories is impaired. Also, the incorporation of these memories into one's narrative in the form of gist or semanticized memories is failing too. Daniel Mograbi, Morris's PhD student from Rio de Janeiro, calls this the petrified self: the story one is able to tell about oneself once Alzheimer's takes hold is stalled. When the narrative self is functioning normally, episodes in one's life line up to tell a story. In its early stages, Alzheimer's prevents the narrative arc from growing any further, limiting it to whatever it was at the time of disease onset. Alzheimer's continues to hack away at the narrative until all one is left with is a set of disconnected episodes. Eventually, even those are gone.

The term "petrified self" did not go down too well among some of their colleagues. "It suggests the person with Alzheimer's is dead or ossified," said Morris. "I have a lot of sympathy for that, since that is not what we meant. We should be careful how we conceptualize people. On the other hand, you can't limit science by political correctness. You can't hide inconvenient truths."

And the truth is that as the narrative self petrifies first and then begins to deteriorate, the person with Alzheimer's reverts back to the critical narrative self, to memories that were formed at a time when the self was being defined most strongly, when its essence was being etched deeply in the body and brain. Alzheimer's, however, ultimately affects even the critical narrative self. Despite Allan's ability to reminisce about his adolescence and early adulthood, Michaele would notice long periods when he would just "disappear, disappear." She'd look into his eyes and find them empty, vacant. All caregivers of Alzheimer's patients would relate to Michaele's experience. "There was just hardly [anyone] there anymore," she told me.

But is that something caregivers are inferring, or is the person with Alzheimer's really unaware? Morris argues that the onus is on science to show that patients are not aware, that they have no self.



Pia Kontos is not comfortable with claims that Alzheimer's patients ultimately have no self. She argues that even in the face of severe cognitive decline evident in Alzheimer's patients, a form of selfhood persists, a precognitive, prereflective selfhood that's embedded in the body. She takes her inspiration from French philosopher Maurice Merleau-Ponty and French sociologist Pierre Bourdieu. "Bourdieu and Merleau-Ponty help [us] think about what the body brings to our engagement with the world that doesn't rely on cognition," she told me.

She has seen examples of such "embodied selfhood" in her research in long-term care settings with people with Alzheimer's disease. One particular observation—of an elderly male resident who was severely cognitively impaired and spoke only in single words, often nonsensical—left a deep impression on her. One day, on Simchat

Torah, a Jewish high holiday to celebrate the Torah, the residents went to the synagogue in the long-term care home. The old man stood in line, waiting to be called to the bimah (pulpit) to sing the prayer. "I saw this gentleman get up in the lineup, and I remember my whole body clutched," said Kontos. "This is going to be a disaster, I thought, because he can't put two words together."

What followed stunned her. When his name was called out, the man confidently walked up to the bimah and recited the prayer with utter proficiency. One could argue that there was some cognition still intact in him that allowed him to do so. But Kontos thinks otherwise.

"The way that I have analyzed it is that there was an orchestration of an event there. There was the touch of the Torah, the presence of the rabbi, the presence of all the congregants, and that elicited in him what Bourdieu has termed 'habitus,' but I term 'embodied selfhood,' and it enabled him to perform in that moment," Kontos said. "If you took that gentleman to his room and asked him to recite the prayer, he couldn't do it."

Embodied selfhood is "the idea that bodily habits, gestures, and actions support and convey humanness and individuality." Merleau-Ponty argued that we are all born with a primordial body that is capable of engaging with the world. "Nothing human is altogether incorporeal," he wrote. He took as an example the skill of touch-typing. If you are a capable touch typist, then typing for you is an activity that does not require you to think about the location of keys on a keyboard. "Knowledge of typing," Merleau-Ponty argues, "is in the hands and manifests itself only when bodily effort is made and cannot be articulated in detachment from that effort."

Bourdieu extended the role of the body beyond its primordial capacity: the body, he said, incorporates our social and cultural habits.

This is what gave rise to the name "habitus." "Habitus comprises dispositions and forms of know-how, which function below the threshold of cognition and are enacted at a prereflective level," writes Kontos, where a disposition is "a way of being, a habitual state . . . a tendency, propensity, or inclination," according to Bourdieu.

Kontos combines Merleau-Ponty's primordial body with Bourdieu's habitus to come to her notion of embodied selfhood. "We all have embodied selfhood; you have it, I have it. It's just that when our cognition is intact, it goes unnoticed; it is sort of in the background. But when we have cognitive impairment, it comes to the foreground," she told me. "This prereflective ability to engage with the world becomes even more important in the face of cognitive impairment because it becomes the primary means of engaging with the world."

Embodied selfhood is blurring the distinction between body and mind; it gives the body its due in making us who we are. Thanks to Descartes, Western neuroscience had elevated the mind, demoting the body to being a mere container, and while neuroscience has slowly distanced itself from Descartes and done away with a stark split between body and mind, the legacy of centuries of such thinking still leads us astray when we attribute to Alzheimer's patients a total loss of self. "Because of Cartesianism, and this constant devaluation of the body, what happens is that when we lose cognitive ability, people jump very quickly to the assumption that there is no self," said Kontos. "But there is still this fundamental dimension of our existence that persists." If we drop Descartes's legacy entirely, and stop distinguishing between body and mind, a new perspective on the self begins to emerge.

So, embodied selfhood involves the brain *and* the body, but in a way that does not necessarily involve cognition. The brain is broadly divided into three physical regions: the cerebral cortex, the cerebellum,

and the brain stem. The cerebellum plays a significant role in procedural memory and in coordinating how our bodies move, and it survives more or less intact until the very late stages of Alzheimer's disease. So, even as the cerebral cortex atrophies and cognition declines, some parts of the brain-body complex continue to store and play out aspects of our selfhood.

Another person living with Alzheimer's disease drove home this message for Kontos. She was an elderly woman, with cognitive impairment so severe that she could not speak, or even dress or feed herself, and was confined to her wheelchair. She was also incontinent. When the nursing staff would wheel her to the dining room and put a bib on her (institutional policy to prevent patients from soiling themselves), she'd struggle to reach under the bib and pull out a string of pearls that she wore, and rest it on top of the bib, where they could be seen. "She'd never begin her meal until she did that," Kontos told me. "She emerges from the depths of dementia with a very strong presence. If that's not self-expression, I don't know what is."

But the making of a complex narrative selfhood (cognitive or embodied) might involve something even more fundamental: the ability to simply be the subject of an experience. When I met Allan, it was clear that despite his incoherent storytelling, he still was someone who was experiencing his own scrambled narrative. It's possible that during the very late stages of Alzheimer's disease, when one's narrative self is completely destroyed, all that is left is the self-as-subject, experiencing those aspects of the self that exist even before a narrative forms. One could argue that the self at its most fundamental is the self-as-subject, and it's not one's narrative. Who or what is this self-as-subject? Sadly, those in the grips of the disease cannot communicate what it's like to be without a narrative—and it'd be too cruel to ask.

We have to turn to clues from elsewhere to understand the basis of this subjectivity. For example, for touch-typing to become an embodied ability and a part of my extended narrative self, do I need to feel the touch of a key at my fingertips and know that *I touched the key*, as opposed to feeling as if someone else was doing it? Or, for that matter, don't I need to feel that my fingers are *my own*? These might seem like outrageous questions, but the next chapter will show that something we take for granted—ownership of body parts—can be disrupted, in experiments and pathologically. When it's the latter, the consequences can be unimaginably dire.



Billy Joel's "It's Still Rock and Roll to Me" is playing on the car radio as I pull into the parking lot of the assisted-living facility to see Clare's father. "*What's the matter with the clothes I'm wearing / Can't you tell that your tie's too wide?*" The California afternoon sun is hot, accentuated by my car's barely functional air-conditioning. Clare is waiting outside the building for me. She punches a security code to enter, a precaution not to prevent outsiders from entering, but rather to keep the residents—mainly patients with Alzheimer's—from wandering out, which they tend to do. We walk down the corridors, past her dad's room (a sign wishing him a happy birthday when he turned ninety last month still hangs on the door). A couple of elderly ladies smile at us and one says, "Good morning." After a moment's pause she adds, "Or good afternoon, I don't know." I can't tell whether she's indulging in some inside humor or not. Either way, it imbues the place with a tender resilience.

We go to see Clare's father in a large hall. It's a scene I have seen only in movies. About twenty men and women, all elderly, are sitting,

some slumped over, some relatively alert. A television set is playing a movie, loudly. It's a recent Michael Caine movie (*Last Love*, I find out later). Clare points to her dad—he's sitting in his own chair, which Clare's mother had brought over so that he'd be more comfortable than in the standard-issue chairs. He is asleep. Clare walks over and gently nudges him. "Dad, Dad," she says. He wakes up perturbed, agitated. Clare reaches for his hands, but he angrily swats at her hand. She tries again to hold his hand, and he reaches out in a handshake gesture, only to twist her hand. She pulls away. He's clearly upset at being woken up. We leave him for the moment and go to his room.

Clare has a key to enter her dad's room—the rooms are locked because otherwise the patients would go around opening doors and entering. The room is simple and sparse. Framed pictures hang on the walls, reminders of Clare's father's life. There's one of him looking handsome at the wheel of a sailboat. There are many family photographs. On the table is a scrapbook made of colored construction paper, the kind a child would make. It's actually something Clare's sister has made for their dad—a simple storybook of some key moments in his life: a photograph of him when he was seventeen; Clare's dad and mother signing the marriage register in Europe; their fellow rowers holding up their oars to form an arch for the bride and groom to walk under as they come out of the church; the family at a beach in Morro Bay, California, after they had come to America—Clare and her sisters are little girls; their home in Minnesota, where Clare grew up; building a barbecue pit at home (one of the few times Clare's dad actually worked with his hands); Clare's dad on the cover of his company's magazine, pictured as a captain on a boat; a trip during a wedding anniversary, around when he turned seventy; and a photograph

of Clare's dad from ten years ago. "There's been a tremendous decline since then," says Clare.

Clare's sister's attempt to jog her father's memory, to give him back his narrative, his coherent story, his self, with this scrapbook hasn't made much of a difference as far as Clare can see.

We go back to see Clare's dad. This time he lets Clare hold his hand briefly. He even squeezes her knuckles. Clare blows a kiss at him, and a few kisses later, he smiles and does the same. I turn to Clare and ask if that means he recognizes her. She says she doesn't know. He hasn't said a word. There's no way to tell. I too try to shake his hand; he doesn't respond at first, but then for a brief moment, he smiles and shakes my hand firmly. He then squeezes my knuckles too. There's no way to tell.

Or maybe there is. For Clare, the knuckle-squeezing takes her back to childhood, when her dad would do that to her playfully. It would make her wince. "Ha-ha-ha, little joke," he'd say, Clare recalled. Could it be that somewhere in that body, Clare's dad still persists—a fragment of his self, a memory, a strong, strapping man still playing with his daughter?



About a month and a half after I met Allan, Michaele took him to check out a board-and-care home. Allan had been incontinent for days, suffering from severe diarrhea. Michaele had spent sleepless nights changing sheets and giving Allan numerous showers. Realizing that they needed help, she drove Allan to visit the care home, which was beautiful, with a nice backyard full of trees overlooking a park. Allan seemed to like it. As they were driving away from the home, Michaele said to him, "Do you think you'll be OK there?" To her surprise, he answered, "I think it's nice, it'll be nice."

He said it with such lucidity that Michaele was immediately guilt-stricken. "Oh, Allan, I feel terrible. I'm going to miss you so much. It's so hard for me to do this. But I know I can't keep going on," she told him.

"That's OK," he said. "We will always be connected no matter what happens."

"That blew me away," Michaele told me. "His ability to communicate with me so clearly that day was phenomenal. He got very quiet again. But I just felt so close to him that day."

Allan would spend just two weeks in the board-and-care home, and then he passed away.

I met Michaele a few weeks after Allan's death. We sat in the same living room where I had first met him. On a small table next to Allan's brown leather sofa, Michaele had set a small white vase full of fresh flowers from their garden, and placed a small clay tortoise atop a few of his favorite books. A candle of lavender-colored wax burned beside a framed photograph of a younger Michaele and Allan. On the sofa's high back, Michaele had carefully draped Allan's brown corduroy jacket.

THE MAN WHO DIDN'T WANT HIS LEG

IS THE FEELING THAT YOU OWN
YOUR BODY AND ITS VARIOUS PARTS
BASED ON REALITY?

The leg suddenly assumed an eerie character—or more precisely, if less evocatively, lost all its character—and became a foreign, inconceivable *thing*, which I looked at, and touched, without any sense whatever of recognition or relation. . . . I gazed at it, and felt, I don't know you, you're not part of me.

—Oliver Sacks

Theoretically you can have a phantom of almost any part of the body, except of course the brain; you can't have a phantom brain, by definition, because that's where we think it's all happening.

—V. S. Ramachandran

This wasn't the first time that David had tried to amputate his leg. When he was just out of college, he had tried to do it using a tourniquet fashioned out of an old sock and strong baling twine. David locked himself in his bedroom at his parents' house, his bound leg