

THE
MAN
WHO
WASN'T
THERE

INVESTIGATIONS INTO
THE STRANGE NEW SCIENCE
OF THE SELF

Anil Ananthaswamy

DUTTON
— est. 1852 —

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

propped up against the wall to prevent blood from flowing into it. After two hours the pain was unbearable, and fear sapped his will. Undoing a tourniquet that has starved a limb of blood can be fatal: injured muscles downstream of the blockage can flood the body with toxins, causing the kidneys to fail. Even so, David released the tourniquet himself; it was just as well that he hadn't mastered the art of tying one.

Failure did not lessen David's desire to be rid of the leg. It began to consume him, to dominate his awareness. The leg was always there as a foreign body, an impostor, an intrusion. He spent every waking moment imagining freedom from the leg. He'd stand on his "good" leg, trying not to put any weight on the bad one. At home, he'd hop around. While sitting, he'd often push the leg to one side. The leg just wasn't his. He began to blame it for keeping him single; but living alone in a small suburban town house, afraid to socialize and struggling to form relationships, David was unwilling to let anyone know of his singular fixation.

David is not his real name. He wouldn't discuss his condition without the protection of anonymity. After he'd agreed to talk face-to-face, we met in the waiting area of a nondescript restaurant, in a nondescript mall just outside one of America's largest cities. A handsome man, David resembles a certain edgy movie star whose name, he feared, might identify him to his coworkers if I revealed it. He had kept his secret well hidden: I was only the second individual whom he had confided to in person about his leg.

The cheerful guitar music in the restaurant lobby clashed with David's mood. He choked up as he recounted his depression. I'd heard his voice cracking when we'd spoken earlier on the phone, but watching this grown man so full of emotion was difficult. The restaurant's

buzzer went off. Our table inside was ready, but David didn't want to go in. Even though his voice was shaking, he wanted to keep talking.

"It got to the point where I'd come into my house and just cry," he had told me earlier over the phone. "I'd be looking at other people and seeing that they already have their lives going good for them. And I'm stuck here, all miserable. I'm being held back by this strange obsession. The logic going through my head was that I need to take care of this now, because if I wait any longer, there is not much chance of a life for me."

It took some time for David to open up. Early on, when we were just getting to know each other, he was shy and polite, confessing that he wasn't very good at talking about himself. He had avoided seeking professional psychiatric help, afraid that doing so would somehow endanger his employment. And yet he knew that he was slipping into a dark place. He began associating his house with the feeling of being alone and depressed. Soon he came home only to sleep; he couldn't be in the house during the day without breaking into tears.

One night about a year before I met him, when he could bear it no longer, David called his best friend. There was something he had been wanting to reveal, David told him. His friend's response was empathetic—exactly what David needed. Even as David was speaking, his friend began searching online for material. "He told me that there was something in my eyes the whole time I was growing up," David said. "It looked like I had pain in my eyes, like there was something I wasn't telling him."

Once David opened up, he discovered that he was not alone. He found a community on the Internet of others who were also desperate to excise some part of their body—usually a limb, sometimes two. These people were suffering from what is commonly called body in-

tegrity identity disorder (BIID). The scientific community is debating whether BIID is the correct name for the condition. They have also suggested xenomelia, from the Greek for "foreign" and "limb," but I'll stick to BIID in this chapter.

The online community has been a blessing to those who suffer from BIID, and through it many discover that their malaise has an official name. With a handful of websites and a few thousand members, the community even has its internal subdivisions: "devotees" are fascinated by or attracted to amputees, often sexually, but don't want amputations themselves; "wannabes" strongly desire an amputation of their own. A further delineation, "need-to-be," describes someone whose desire for amputation is particularly fierce.

It was a wannabe who told David about a former BIID patient who had been connecting other wannabes to a surgeon in Asia. For a fee, this doctor would perform off-the-books amputations. David contacted this gatekeeper on Facebook, but more than a month passed without a reply. As his hopes of surgery began to fade, David's depression deepened. The leg intruded more insistently into his thoughts. He decided to try again to get rid of it himself.

Rather than resorting to a tourniquet, this time he settled for dry ice, one of the preferred methods of self-amputation among the BIID community. The idea is to freeze the offending limb and damage it to the point that doctors have no choice but to amputate. David drove over to his local Walmart and bought two large trash cans. The plan was brutal but simple. First, he would submerge the leg in a can full of cold water to numb it. Then he would pack it in a can full of dry ice until it was injured beyond repair.

He bought rolls of bandages, but he couldn't find the dry ice or the prescription painkillers he needed if he was going to keep the leg in

dry ice for the required eight hours. David went home despondent, with just two trash cans and bandages, preparing himself mentally to go out the next day to find the other ingredients. The painkillers were essential; he knew that without them he would never succeed. Then, before going to bed that night, he checked his computer.

There it was: a message. The gatekeeper wanted to talk.



We are only just beginning to understand BIID. It hasn't helped that the medical establishment generally dismisses the condition as a perversion. Yet there is evidence that it has existed for hundreds of years. In a recent paper, Peter Brugger, the head of neuropsychology at University Hospital Zurich, Switzerland, cited the case of an Englishman who went to France in the late eighteenth century and asked a surgeon to amputate his leg. When the surgeon refused, the Englishman held him up at gunpoint, forcing him to perform the operation. After returning home, he sent the surgeon 250 guineas and a letter of thanks, in which he wrote that his leg had been "an invincible obstacle" to his happiness.

The first modern account of the condition dates from 1977, when *The Journal of Sex Research* published a paper on "apotemnophilia"—the desire to be an amputee. The paper categorized the desire for amputation as a paraphilia, a catchall term for deviant sexual desires. Although it's true that most people who desire such amputations are sexually attracted to amputees, the term "paraphilia" has long been a convenient label for misunderstandings. After all, at one time homosexuality was also labeled as paraphilia.

One of the coauthors of the 1977 paper was Gregg Furth, who eventually became a practicing psychologist in New York. Furth him-

self suffered from the condition and, over time, became a major figure in the BIID underground. He wanted to help people deal with their problem, but medical treatment was always controversial—often for good reason. In 1998, Furth introduced a friend to an unlicensed surgeon who agreed to amputate the friend's leg in a clinic in Tijuana, Mexico. The patient died of gangrene and the surgeon was sent to prison. Around the same time, a Scottish surgeon named Robert Smith, who practiced at the Falkirk and District Royal Infirmary, briefly held out legal hope for BIID sufferers by openly performing voluntary amputations, but a media frenzy in 2000 led British authorities to forbid such procedures. The Smith affair fueled a series of articles about the condition—some suggesting that merely identifying and defining such a condition could cause it to spread, a form of cultural contagion.

Undeterred, Furth found a surgeon in Asia who was willing to perform amputations for about \$6,000. But instead of getting the surgery himself, he began acting as a go-between, putting sufferers in touch with the surgeon. He also contacted Michael First, a clinical psychiatrist at Columbia University in New York. Intrigued, First embarked on a survey of fifty-two patients. What he found was instructive. The patients all seemed to be obsessed by the thought of a body that was different in some way from the one they possessed. There seemed to be a mismatch between their internal sense of their own bodies and their actual physical bodies. First, who would later lobby to have BIID more widely recognized, became convinced that he was looking at a disorder of identity, of the sense of self.

"The name that was originally proposed, 'apotemnophilia,' was clearly a problem," he told me. "We wanted a word that was parallel to gender identity disorder. GID has built into the name a concept that

there is a function called gender identity, which is your sense of being male or female, which has gone wrong. So, what would be a parallel notion? Body integrity identity disorder hypothesizes that a normal function, which is your comfort in how your body fits together, has gone wrong."

In June 2003, First presented his findings at a meeting in New York. Robert Smith, Furth, and many BIID sufferers attended the meeting. One of them was David's gatekeeper, whom I'll call Patrick.

Without much warning, Furth walked up to Patrick and his wife with a startling proposition. "We are standing there eating our sandwich, and he says to me, 'Would you be interested in a surgical option?'" Patrick had felt the pressure of BIID for most of his life. He didn't have any reservations. "Hell, yes. Yes, yes, yes, no question about it." To this day, Patrick doesn't know why Furth singled him out. Patrick is not a religious man, but he felt a higher power was giving him his due.

The next evening, Patrick and his wife went over to Furth's apartment for an evaluation. Furth grilled Patrick to make sure he was for real. Was Patrick's desire due to BIID or a sexual fetish? How did it affect his life? For two hours the questions flowed. Patrick answered them, scared that he'd "flunk the evaluation." He didn't, and Furth agreed to make the recommendation. That was where it all began. Ten months later, he had the surgery he craved. And less than a year after that, Patrick had become the gatekeeper himself.

• • •

Sitting at home in a small, somewhat rural American town not too far from the ocean, Patrick recalled the day his wife found out about his obsession. It was during the mid-'90s. As with almost all BIID suffer-

ers, Patrick was fascinated with amputees, so he began downloading pictures of them off the Internet and printing them out. One day his wife was sitting in front of their computer, while Patrick sat in a wing-back chair. She noticed a pile of printouts. They were images of men, but "completely clothed, no nudes or anything like that." It was an awkward moment. "She was thinking that maybe I was gay," Patrick recalled. "I must have been crimson." Patrick asked her to take a closer look. She did, and soon realized that the men were all amputees.

Patrick told his wife that he had felt odd about his leg since he was four years old, a feeling that eventually grew into an all-consuming desire to be rid of it. It was a shock: they had been married for decades, and the revelation that he had been hiding something from her for all those years was hard to take. But his confession also brought relief. For more than four decades Patrick had suffered alone. Growing up in small-town America, with conservative parents, in an era when "people didn't believe in going and seeing mental-health professionals," Patrick was mystified by what he felt. By the early '60s, as a teenager, his obsession with amputees and amputations took him to a library in the nearby state capital, where he hoped to find books on the subject. To his surprise, most of the pictures of amputees had been cut out and stolen. At that moment he realized that he wasn't the only person who was consumed by this strange obsession.

"There had to be somebody else out there," Patrick told me, "but how could I find out who?"

As time went on, Patrick struggled with his thoughts about his leg: "How can I get rid of it? What can I do? How can I do it? I don't want to die in the process." Seeing a picture of an amputee, or worse, seeing an amputee on the streets, would ratchet up his emotions. "It would just drive me nuts," he told me. "That could last for several days. All I

could think about was how I could get rid of my leg." His anxiety led him to make deals with God and pacts with the devil: "Take my leg, save somebody else's," he implored. Yet through it all, for the first four and a half decades of his life, he told no one. The loneliness was almost too much to bear.

Less than a year before his wife's discovery, he had stumbled upon an anonymous classified ad in a local city newsletter. The person who placed it admitted a desire to amputate a limb; he was a wannabe. Patrick wrote to the PO box that was listed and began a correspondence with the man. Eventually they met, and the wannabe told him about others who were seeking amputations. It was deliverance. "Oh my God, I'm not alone with this anymore," Patrick recalled thinking. "I'm not nuts."

Yet finding others who shared his condition did not lessen his need. If anything, Patrick's desperation grew. He considered a DIY amputation. He had heard of people who had lain down on train tracks and let a train run over their limbs, or who had blown their legs off with a shotgun. "The trouble with a train is that if the train is moving at a good clip, you can kill yourself very easily, because it can pick you up and spit you out," he said. "I really didn't want to die in the process and not find out what it was like to live with one leg."

Another wannabe who had done a DIY amputation suggested Patrick practice first, so Patrick decided to get rid of part of his finger as a prelude to amputating his leg. With a pen and a rubber band, he made a tourniquet for one of his fingers and stuck it into a thermal cup full of ice and alcohol. After part of the finger became numb and Patrick was unable to bend it, he took a hammer and chisel and chopped off the bit above the first knuckle. He even smashed the detached digit. "So they couldn't reattach it even if they wanted to," Patrick told me.

Crushing the amputated digit also aided in the cover-up: hospital staff were told that a heavy object had fallen on the finger. When a doctor injected his injured finger with a painkiller, Patrick pretended that the needle hurt. His finger was still too numb to feel any pain.



It was about a decade ago that Patrick finally made it to Asia to see the surgeon Greg Furth introduced him to. He was admitted to the hospital on a Friday evening and had to wait until Saturday evening to be wheeled into surgery. "The single longest day of my life," he told me. He awoke from his anesthesia the next day. "I looked down and couldn't believe it. It was finally gone," he said. "I was ecstatic." His only regret in the ten years since his amputation is that he didn't get it when he was younger. "I wouldn't want my leg back for all the money in the world, that's how happy I am."

This comfort with his condition is reflected at home. Just before the surgery, his children gave him a Ken doll, which he keeps in a plastic box stuffed with scrapbooks of photographs of amputees that he collected in his younger days. The doll wears a pair of red shorts; one of its legs ends above the knee, in a stump wrapped with a white gauze bandage. In Patrick's house, I saw a decorative skeleton hanging off a chandelier and didn't think much of it. "Look more closely," he urged. Only then did I notice that it, like Patrick, was missing part of a leg and part of one finger. Then there was a statue of Michelangelo's *David* on the mantelpiece. It, too, was missing part of a leg. The family had acknowledged Patrick's suffering and was celebrating his freedom from BIID. Patrick now seemed genuinely comfortable with his body.

This feeling of relief and release is a sentiment expressed by just

about every BIID amputee who has been studied by scientists. That evidence ought to allay at least one fear that ethicists have expressed about BIID—that once you amputate a healthy limb, the patients will eventually come back for more. In nearly all accounts, they don't, unless from the very beginning their BIID involves multiple limbs.

Furth, for his part, was diagnosed with cancer and died in 2005 without ever getting his own amputation. When he vetted Patrick for surgery, Patrick told him that after his amputation he would try to help the others he knew were out there. Nearing death, Furth called Patrick. Would he take over the gatekeeping duties for the surgeon in Asia? Patrick agreed to do so, and for nine years he has acted as the go-between for BIID sufferers. One way or another, they eventually find him. And just before he could use dry ice on his leg, David found him too.



A year or so before Patrick's operation, a psychologist asked him if he would take a pill to make his BIID go away, should such a treatment exist. It took a moment for him to reflect and answer: maybe when he had been a lot younger, but not anymore. "This has become the core of who and what I am," he said.

This is who I am. Everyone with BIID that I interviewed or heard about uses some variation on those words to describe their condition. When they envision themselves whole and complete, that image does not include parts of their limbs. "It seems like my body stops mid-thigh of my right leg," Furth told the makers of a 2000 BBC documentary, *Complete Obsession*. "The rest is not me."

In the same film, the Scottish surgeon Robert Smith tells an interviewer, "I have become convinced over the years that there is a small

group of patients who genuinely feel that their body is incomplete with their normal complement of four limbs.”

It's difficult for most of us to relate to this. Your sense of self, like mine, is probably tied to a body that has its entire complement of limbs. I can't bear the thought of someone taking a scalpel to my thigh. It's *my* thigh. I take that sense of ownership for granted. This isn't the case for BIID sufferers, and it wasn't the case for David. When I asked him to describe how his leg felt, he said, “It feels like my soul doesn't extend into it.”

Neuroscience has shown us over the past decade or so that this sense of ownership over our body parts is strangely malleable, even among normal healthy people. In 1998, cognitive scientists at Carnegie Mellon University in Pittsburgh performed an ingenious experiment. They sat subjects down at a table and asked them to rest their left hands on it. A rubber hand was placed next to the real hand. The researchers put a screen between the two, so that the subjects could see only the rubber hand but not the real hand. The researchers then used two small paintbrushes to stroke both the real hand and the rubber hand at the same time. When questioned later, the subjects said that they eventually felt the brush not on their real hand but on the rubber hand—even though they were fully cognizant at all times that their real hand was being brushed. More significantly, many said they felt as if the rubber hand was their own.

The rubber-hand illusion illustrates how the way we experience our body parts is a dynamic process, one that involves constant integration of various senses. Visual and tactile information, along with sensations from joints, tendons, and muscles that give us an internal sense of the relative position of our body parts (neuroscientists call this sense proprioception), are combined to give us a sense of owner-

ship of our bodies. This feeling is a crucial component of our sense of self. It's only when the process that creates this sense of ownership goes awry—for example when the brain receives conflicting sense information, as in the rubber-hand illusion—that we notice something is amiss.

It's likely that the brain has different mechanisms to create a sense of ownership. For instance, as we'll see in the next chapter, the brain creates a sense of being the initiator of one's thoughts and actions—the feeling that *you* performed an action when you picked up a bottle, or that *you* thought something and it felt like *your* thought, and not someone else's. This so-called sense of agency is key to owning your actions and your thoughts (when it goes wrong, the consequences can be debilitating, including psychotic delusions and schizophrenia).

So, if we can feel as if we own something as inanimate as a rubber hand, can we own something that doesn't exist? Seemingly, yes. Patients who have lost a limb can sometimes sense its presence, often immediately after surgery and at times even years after the amputation. In 1871, an American physician named Silas Weir Mitchell coined the phrase “phantom limb” for such a sensation. Some patients can even feel pain in their phantom limbs. By the early 1990s, thanks mainly to some pioneering work by neuroscientist V. S. Ramachandran of the University of California, San Diego, it was established that phantom limbs were an artifact of body representation in the brain gone wrong.

The idea that our brain creates maps or representations of the body emerged in the 1930s, when Canadian neurosurgeon Wilder Penfield probed the brains of conscious patients who were undergoing neurosurgery for severe epilepsy. He found that each part of the body's outer surface has its counterpart on the surface of the brain's cortex: the more sensitive the body part—say, hands and fingers, or the face—

the larger the brain area devoted to it. As it turns out, the brain maps far more than just the body's outer surface. According to neuroscientists, the brain creates maps for everything we perceive, from our bodies (both the external surface and the interior tissues) to attributes of the external world. These maps compose the objects of consciousness.

The presence of such maps can explain phantom limbs. Though patients have lost a limb, the cortical maps sometimes remain—intact, fragmented, or modified—and they can lead to the perception of a limb, along with its potential to feel pain. Even people born without limbs can experience phantom arms or legs. In 2000, Peter Brugger wrote about a forty-four-year-old highly educated woman, born without forearms and legs, who nonetheless had experienced them as phantom limbs for as long as she could remember. Using fMRI and transcranial magnetic stimulation (TMS), Brugger's team verified her subjective experience of phantom limbs and showed that body parts that were absent from birth could still be represented in sensory and motor cortices. "These phantoms of congenitally absent limbs are *animation without incarnation*," Brugger told me. "Nothing had ever turned into flesh and bones." The brain had the maps for the missing body parts even though the actual limbs had failed to develop.

When confronted with BIID, Brugger saw parallels to what the forty-four-year-old woman experienced. "There must be the converse, which is an *incarnation without animation*," he said. "And this is BIID." The body had developed fully, but somehow its representation in the brain was incomplete. The maps for a part of a limb or limbs were compromised.

Recent studies have borne out this idea. Neuroscientists are particularly interested in the right superior parietal lobule (SPL), a brain region thought to be vital to the construction of body maps. Brugger's

team has found that this area is thinner in those with BIID, and others have shown that it may be functioning differently in those with the condition. In 2008, Paul McGeoch and V. S. Ramachandran mapped the activity in the brains of four BIID patients and control subjects. The researchers tapped the feet of the control subjects and watched the SPL light up. But the BIID patients were different: the right SPL showed reduced activity when the disowned foot was tapped, only lighting up normally when the tap was on the other foot.

"What we argue is that in these people something has gone wrong in the development, either congenitally or in the early development, of this part of the brain," McGeoch told me. "This limb is not adequately represented. They find themselves in a state of conflict, a state of mismatch that they can see and feel."

There are almost certainly other parts of the brain involved. Recently, scientists reviewed a number of "body-ownership" experiments, including the rubber-hand illusion, and identified a network of brain regions that integrate sensations from the body and its immediate surroundings and sensations related to the movement of our body parts. The network includes a clutch of areas, from cortical regions responsible for motor control and the sense of touch all the way to the brain stem. This network, they suggest, is responsible for what they call the "body matrix"—a sense of our physical body and the immediate space around it. Because the network helps maintain the internal physiological balance of the body, it reacts to anything that threatens the body's integrity and stability. Intriguingly, the physical differences in the brains of BIID patients that Brugger identified include changes in nearly all the parts of this network. Could BIID result from alterations to this body-matrix network? Brugger's team thinks so.

It's crucial to emphasize that these findings are *correlations*—they don't prove that the neural anomalies are the *cause* of BIID. It's a caveat to keep in mind throughout this book. There is a tendency within neuroscience toward neurobiological reductionism, especially in the study of disorders, by viewing the brain-mind relationship as a one-way street, with the brain influencing mental activity, and not the other way around. fMRI or PET scans usually tell us about the relative change in activity in specific brain regions in a person with some disorder when compared with healthy controls. But except in clear-cut cases of neurological damage, such scans give us correlations between brain activity and a person's condition; they don't definitively establish whether the observed anatomical and functional aberrations seen in brain scans came first and caused someone's condition (such as BIID) or whether ceaseless mental activity (thinking obsessively that "this leg is not mine," for example) led to the changes in the brain.

Then there is the question of how body states and body-matrix networks translate into a sense of self. And for BIID patients, how does a skewed body map lead to the desire for amputation?

Philosopher Thomas Metzinger provides an insight into why someone with BIID might disown a body part, and it has to do with his ideas about the self. "'Owning' your body, its sensations, and its various parts is fundamental to the feeling of being someone," Metzinger wrote in his book *The Ego Tunnel*. In his theory, the brain creates a model, a representation of the environment in which the body exists. Embedded within this model of the world is a model of the self: a representation of the organism itself, which is used to "regulate its interaction with the environment" and to maintain the organism in an optimal state of functioning.

That the brain must create such models follows from a classic 1970 paper that showed mathematically that "any regulator . . . must model what it regulates." So, if the brain is trying to regulate the body, it must model the body, and this is the self-model.

Crucially, only a subset of this self-model enters conscious awareness. This is what Metzinger calls the phenomenal self-model (PSM). The contents of this model are what we are conscious of, including bodily sensations, emotions, and thoughts. Put another way, the content of the PSM is our ego, our identity as subjectively experienced. At any given moment, there might be body states that are part of the self-model but not part of the PSM, in which case we would not be conscious or subjectively aware of those body states. And the contents of these models, whether of the world, the self, or the phenomenal self, are constantly changing. Also, what separates the contents of the world-model from the contents of the PSM is the property of *mineness*: objects in the world-model don't feel like mine, while those in the PSM, whatever they are, by definition feel like they belong to me.

If Metzinger is right, then before the rubber-hand illusion sets in, the lifeless hand that one is seeing is part of one's world-model, but not of the PSM. So, it lacks a sense of belonging to *me*. We come under the grip of the illusion because the experiment modifies our PSM: our brains replace the representation of the real hand with a representation of the rubber hand, which is now embedded in our phenomenal self-model. Since anything in the PSM has the subjective property of *mineness*, we feel as if the rubber hand belongs to us. In BIID, it's likely that a limb or some other body part is misrepresented or underrepresented in the PSM. Lacking the property of mineness, it is disowned (it's intriguing to think that Cotard's syndrome could also be due to a messed-up phenomenal self-model).

Metzinger's ideas give us a clue to why someone with BIID might want to amputate a limb that doesn't feel like it belongs. My self—as defined by the content of the PSM—is not just my subjective identity; it is also the basis for the boundary between what's mine and everything else, between me and not-me. "It's a tool and a weapon," said Metzinger, when we spoke on the telephone. "It's something that evolved to constantly preserve and sustain and defend the integrity of the overall organism, and that includes drawing a line between me and not-me on very many different functional levels. If there is a misrepresentation in the brain that tells you this is not your limb, it follows that this will be a permanently alarming situation."

McGeoch, Ramachandran, and their colleagues showed this in a simple and elegant experiment. They studied two people who wanted voluntary amputations: a twenty-nine-year-old man who desired an amputation below his right knee; and a sixty-three-year-old man who wanted amputations below his left knee and below his right thigh. One of the curious things about BIID is that most sufferers can precisely delineate their limb into the part that feels their own and the part that doesn't. And this separation is stable over time (suggesting that the condition is neurological rather than psychological, according to Ramachandran's team). In their study, the researchers recorded skin conductance response (SCR) using electrodes attached to the subjects' hands, when they were pricked with a pin either below or above the "desired line of amputation."

SCR cannot be willfully controlled. Most people, when they are touched or when they hear a noise or when they perceive emotionally salient stimuli, will show an increased SCR. Ramachandran's study showed that when their BIID subjects were pricked on the part of the limb that they felt was foreign, the SCR was two to three times greater

than when the pinprick was on the normal part of the limb. One interpretation of this data is that the pinprick on the part they wanted amputated was felt as more threatening.

Brugger's team also found something similar. When BIID patients were tapped simultaneously on both the foreign-feeling and normal parts of their limbs, they reported feeling the taps on the rejected parts earlier: their brains were prioritizing these tactile stimuli.

Both studies suggest a hyperawareness of the disowned parts of limbs. It's as if the brain of BIID sufferers is paying extra attention to body parts that feel alien. "It's like an active foreign part in their bodies, which attracts attention, therefore it is prioritized in their temporal lobe," said Brugger. "It makes sense, in retrospect."

It is, however, deeply ironic that the foreign-feeling body part would be attracting more attention than the rest of the body. Contrast BIID with a condition called somatoparaphrenia, in which people often deny ownership of a leg or arm, or even an entire side of their body. The delusion often arises because the person has suffered paralysis of one side of the body and is also sometimes unaware of the paralysis. But in BIID, there is no such functional problem with the body part. So, the brain's increased attention to it makes sense only if you accept that the leg or the arm is not part of the bodily self constructed by the brain. BIID is also telling us that even though we can lose the sense of ownership over body parts, there is still an "I"—the self-as-subject—that experiences the lack of *mineness* of a limb. It's unfortunate that the estranged body part becomes an object of obsession, as would anything foreign that clung to one's body, an obsession that eventually leads some to amputation.

Visceral negative reactions are common when people first hear about voluntary amputations. About fifteen years ago, when media attention to BIID happened to be at a peak, bioethicist Arthur Caplan, then of the University of Pennsylvania, called it “absolute, utter lunacy to go along with a request to maim somebody.”

More than a decade later, there is still a debate raging in the pages of academic journals about the ethics of voluntary amputations. Is it analogous to body-modifying cosmetic surgeries, such as breast reduction, as BIID sufferers themselves have argued? Some bioethicists say no, since amputation entails a permanent disability. Others point out that cosmetic surgery can also be disabling, as when breast reduction results in the inability to breast-feed. Some have compared BIID to anorexia nervosa as the best, if a somewhat imperfect, analogy, because both involve body-image discrepancies. According to this line of argument, amputations should be denied just as anorexics are sometimes fed against their will. The retort to this is that anorexics are clearly delusional about their bodies, as objective measures can show their body weight to be dangerously low. There is no accepted objective measure of a BIID patient's internal feeling of bodily mismatch.

The debate continues, partly because BIID is not a medically recognized disorder. There's also a lack of data about how voluntary amputations affect the lives of patients. Yet David's surgeon, an orthopedic specialist, has made up his mind.

Dr. Lee—which is not his real name—is in his mid-forties, friendly, with an easy laugh. He seems at peace with his secret practice. When a BIID patient first approached him six years ago, he'd had his doubts, so he researched BIID as thoroughly as he could and communicated with the patient for several months before deciding to do the amputa-

tion. He knew he would be risking his medical license. A religious man, he and his wife even prayed on it, eventually putting some of the onus of the decision on higher powers. “*God, if you think this is not right, then put some hindrance,*” he remembers thinking. “*I don't know what it is, but put some hindrance.*” So far, things have gone smoothly, and he's taking that as divine sanction.

Dr. Lee is convinced that what he does is ethical. He has no doubt that BIID patients are suffering deeply. On the question of whether to amputate to relieve their suffering, he invokes the World Health Organization's definition of health: a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. As far as he can tell, people with BIID are not healthy; there is no nonsurgical cure in sight and no evidence that psychotherapy helps. Michael First, in his 2005 survey of fifty-two BIID patients, reported that 65 percent of them had seen psychotherapists, but it had no effect on their desire for amputation (though it's also true that half of them did not tell their psychotherapists about such desires).

Of course, there's also the question of whether BIID sufferers are psychotic or delusional. Again, the scientists who have studied these individuals say that they are neither. Dr. Lee insisted that his patients have not been psychotic (and as we'll see in the next chapter, psychosis in schizophrenia involves a profound alteration of one's experienced reality; no one with BIID I talked to said this was the case for them).

On the contrary, Dr. Lee said, many of his patients were high-functioning individuals, including a pilot, an architect, and a doctor. And for Dr. Lee the proof that BIID is a real condition can be found in the near-instant change he has observed in his patients after the surgery, which contrasts strongly with those who have to undergo invol-

untary amputations because of, say, a car accident. Involuntary amputations are traumatic to even the strongest of people, and those people can become severely depressed as a result. "Then you have these BIID people who crutch unbelievably after the first day after surgery."

Paul McGeoch, who has studied his fair share of BIID patients, has the same opinion. "They are universally happy. I have never heard of one who is not pleased to have a limb amputated," he said. But as convinced as Dr. Lee seemed, he repeatedly stressed to me: "I'll stop the moment I get my first patient who feels remorseful about the surgery. So far, none have."

If BIID were ever to be legitimized and voluntary amputations to become legal, Dr. Lee knows that his clandestine program would end. "I'd be so glad if ever that happened. I won't have to deal with the tension anymore," he said. "Right now, I'm torn between the tension of doing the surgery, and the tension of helping them." Then, in a momentary lapse of caution, he admitted that he would miss the surgeries: "Maybe that's the weirdo in me."

Would he miss the money, which amounts to about \$20,000 per operation? The answer was an emphatic no. He said he made the same amount doing legal surgeries for foreign health tourists and that he had a flourishing local practice. He pointed out that his fee covered everything: hospital costs, payments to his fellow surgeons, even some meals and sightseeing for his patients. "You are not paying for the surgery. You are paying for all the risks involved," he said. "You have to keep everybody happy. We are not talking peanuts here. If this gets out, we all lose our licenses." He said it was a risk he's willing to take, as long as his patients are happy.

• • •

The morning that David was scheduled for surgery I went to meet him and Patrick in their hotel suite. We had flown thousands of miles to be there, in a crowded Asian city. Outside the hotel, the weather was hot and muggy, the traffic heavy. Luxury cars and jalopies jostled for street space alongside buses and two-wheelers. Diesel fumes stung my nostrils. A fetid stream wound its way between high-end hotels and office buildings. Inside the hotel, the wood-paneled suite was air-conditioned, hushed.

I had spent the night thinking about David's surgery, and all I had felt was anxiety. I imagined the fear that David must be experiencing: fear of surgery, fear of confrontations with family and friends, fear of disability. But that morning David himself showed no such emotions. He said he had moved beyond those worries. Instead, he fretted about the paperwork. Whom should he put down as emergency contacts? Should he divulge their addresses and phone numbers? Patrick suggested putting down the wrong numbers; maybe change a digit or two. "You'll have to get used to lying," he said.

Questions kept occurring to me. I asked David if he had been evaluated by a psychiatrist. Usually, Patrick recommended someone for surgery only after a psychiatrist confirmed that he or she was suffering from BIID. David said no. Patrick had used his own judgment in recommending him to the surgeon, saying that he saw himself in David—the same agony, the same mental torture. Plus, David couldn't afford a psychiatric evaluation. He had to scrape and scrounge and go deeply into debt to come up with the \$25,000 needed to cover the surgeon's fees, the airfare, and ten days of hotel accommodation for two.

Dr. Lee had agreed to the surgery based on Patrick's recommendation. The two had been working together ever since they met via the

BIID network about six years ago. David was thankful for Dr. Lee's help. "As you know," he told me in the hotel room, "I was in a DIY mode, where I was going to hurt myself." Suddenly, David started sobbing. Patrick consoled him; David apologized. "Every time I talk about hurting myself, it makes me cry," he said. David again expressed certainty that if the surgery didn't go through, he would attempt cutting his leg off himself. "I can't go on any longer."

The surgeon picked us up in the early afternoon. Given that David's procedure would require subterfuge to get past hospital staff and nurses, Dr. Lee appeared surprisingly calm. "Have to be," he replied when I asked him later about his demeanor. "Cannot show the patient that I'm nervous." He drove us to his house, ushered us into the living room, and asked David to sit down.

Dr. Lee laid out the plan: he would get David admitted to a hospital, saying he needed surgery for a vascular disorder. The unwitting staff would then prepare the patient for an ordinary operation—and then, under the surgical lights, Dr. Lee would say that the leg needed removing, and conduct the amputation. Inside, the anesthesiologist and other surgeons would be in on the plan; the nurses would not know.

In his living room, Dr. Lee laid an old garment on the floor, and set David's foot on it. Working swiftly, he bandaged the foot, ankle, and calf as a precaution. It wouldn't do to have curious hospital staff see that the foot was healthy. He wrote the admitting order on his prescription pad and instructed David in the sequence of symptoms he ostensibly had endured over the past few days: pain, followed by some cramping, and eventually numbness. This was for the benefit of the hospital admissions staff. The diagnosis that these symptoms implied would give Dr. Lee the option of amputating during surgery, a

judgment that could not be questioned by anyone who wasn't in the operating room.

We drove to a small hospital on the outskirts of the city. The high-rise hotels gave way to low-slung buildings and occasional homes with makeshift tin roofs alongside unpaved muddy alleys. The hospital itself was on a major road lined with an odd assortment of shops: a butcher, a pawnshop, an electronics repair outfit, and a hairdresser who promised safe and effective hair straightening.

Dr. Lee was not on staff at this hospital; like many doctors in private practice he had surgical privileges at a number of different hospitals. He dropped us off outside. David, now on crutches, would have to get past the hospital staff. Would they buy his story? We walked into the emergency room. It was a simple affair. Ten iron-frame beds and mattresses covered with spotless sheets were separated by thick curtains. This was not a high-tech, First-World ER, but it was clean and functional.

A nurse asked David to sit down and asked what was wrong with him. He gave her Dr. Lee's admitting order. The attending physician, a bespectacled man in a blue-striped shirt with a stethoscope around his neck, took the order and frowned as he read it. He leaned over the counter to take a look at David's leg. He noted the bandaging and asked if David had suffered an accident. No, said David, and he quietly repeated the sequence of symptoms. The man got up and walked away.

David was subdued. Patrick, wearing his prosthetic leg, appeared to be feeling fine; he had been through this scenario many times. David, beneath his quiet demeanor, was nervous, as was I, even though I was just an observer. My mind raced through all that could go wrong. What if the attending doctor asked more questions? What were the three of us, two of whom were on crutches, doing in this part of the

world? What if they called the police? Then, once David was done filling in the paperwork, a nurse brought him a wheelchair. She inserted a catheter into David's left hand and hooked it up to an IV bag hanging off of a pole on the wheelchair. She left. I looked at Patrick. "I can't believe it's really happening," he whispered in relief. A male nurse came in, and we got up and followed him as he wheeled David up to his hospital room. They had bought the story.

In the hospital room, we sent the surgeon a text message to say that David had checked in. Dr. Lee told me later that his own nervousness usually sets in the moment he receives that message. Now all was in motion.

As we waited in the hospital room, Patrick started giving David advice about life as a leg amputee. Don't ever close your eyes when you're standing without support, he said. You'll lose balance and topple over. Always carry powerful painkillers: stumbling and landing on your stump can be excruciating.

A nurse came in and informed David that the doctor would operate in a few hours, then left us alone again. We counted the saline drops dripping into David's veins: about twelve drops per minute. I asked David about his cover story for when he got back home. He said he would tell people at home the story he had told the hospital. Dr. Lee would provide him a full medical report to take back. Patrick recalled his own cover story: he'd picked up a rapidly spreading infection called St. Anthony's Fire while on vacation; the rampant infection turned the leg gangrenous, leading to the amputation. It had worked well for him. Then Patrick told David to do something one last time, for once the operation was complete, he would never be able to do it again: cross his legs. David did so. It was as if we were mourning an impending loss with a collective moment of silence.

Soon, two male nurses wheeled in a gurney. David lay down on it and he was taken away to surgery. Patrick gave him a thumbs-up. I didn't know what to say, so I just muttered, "Good luck," under my breath.



The hospital has gone quiet, and empty benches line the dimly lit corridors. Only the operating room shows signs of activity. David lies on the operating table, anesthetized and oblivious to pain. An overhead surgical lamp illuminates his upper thigh. Dr. Lee picks up a scalpel and makes a long, deep incision precisely where David had requested, in a leg that is athletic, muscular, healthy. The surgeon swiftly cuts through muscle, working hard. He cauterizes the smaller blood vessels as he goes while keeping clear of the large veins, arteries, and nerves. He pulls at the nerves, teases them free of the surrounding muscles, cuts, then lets go. The nerves retract into the soft tissue of the upper thigh like rubber bands. He clamps the large blood vessels, snips them, and ties up the proximal and distal ends, the proximal end three times for peace of mind. The surgery is taking longer than anticipated because the leg is so robust, engorged with blood. Finally, he slips a wire saw under the femur. An assistant presses down on the leg. Dr. Lee begins sawing and soon pulls the saw through the strongest bone in the body. He then attends to the blood vessels, nerves, muscle, and skin on the underside of the bone until the leg is finally detached. It is time to suture. First he sews up the muscles, then the fascia, the strong fibrous tissue surrounding the muscles. Suturing the fascia correctly is critical, because mistakes can lead to muscle herniation, a serious complication. Finally, the surgeon stitches up the skin and the subcutaneous tissues. Where once there was a leg, only a stump remains.



I wasn't in the operating room that night. But I did walk the empty corridors outside, trying to peer discreetly over the frosted glass panes of the doors leading into the OR. I have thought about the surgery (which Dr. Lee had described to me in detail) many times since. Each time I have felt fear and sadness. Here was a perfectly healthy man with a perfectly healthy leg, yet he went under the knife voluntarily, in a foreign country. He trusted a surgical team that worked under a cloak of deception. How much must a man suffer to come to this: lying by himself on an operating table, attended only by strangers, in a small, obscure hospital thousands of miles from his home in America?



Patrick was asleep when I heard the knock on the door. It was more than three hours since David had been wheeled away. It was a male nurse in surgical robes and rubber gloves. He turned to Patrick and said, "The leg has to be buried as soon as possible." He needed money to take care of the burial. Patrick handed him some cash. "Do you want to see the leg?" the nurse asked. "It's already in the box." Patrick didn't. The nurse left. "Well, he's an amp now. I'm glad," said Patrick. "It's what he wanted. It's what he needed."

Dr. Lee appeared soon after. The surgery went well, he said, though it had taken longer than usual. David was fine and lay asleep in recovery. Dr. Lee offered to give me a ride back to my hotel, and I accepted. During the ride he talked about David's long operation. "His muscles were well built," said Dr. Lee. "They contract and they also bleed more. You have to be careful." Still, there was the satisfaction of a job well done. "What's fascinating is that you can really see the transforma-

tion," he said. He meant the change in the demeanor of his BIID patients after surgery. "You'll notice it tomorrow."

The next day, I couldn't wait to get back to the hospital. I bought a bar of bittersweet chocolate for David and hailed a taxi. When we arrived, I walked in through the front door, past the ER, and paused for a moment at the frosted glass doors of the operating room. Then I went to David's room and knocked on the door. Most patients would be flat on their backs recovering after such a major surgery, but David was sitting up in his bed, his stump heavily bandaged and covered in white gauze. He was still on an IV. Tramadol, a narcotic-like analgesic, was dripping into his veins. He was tethered to a urine bag. He looked tired, but then it was only twelve hours since the operation. I shook his hand and gave him the chocolate. David opened the wrapper, broke off a piece, and began to eat. He sat on the hospital bed as if nothing dramatic had happened the night before. Our conversation eventually wore him out. He fell asleep.

When I returned the next day, the IV and the urine bag were gone. A pair of crutches lay next to David's bed; he had already crutched to the bathroom and back, just as the surgeon had said he would. He smiled and laughed easily as we spoke. The tension that had lined his face all the time I had known him was gone. I sensed relief, happiness.

Months later, I exchanged emails with David. He said he had no regrets. It was as if for the first time in his life, David was whole.