



**PROJECT MUSE<sup>®</sup>**

# Brain Memoirs, Neuroscience, and the Self: A Review Article

Jason Tougaw

**Antonio Damasio.** *Self Comes to Mind: Constructing the Conscious Brain.* New York: Pantheon, 2010. 384 pp. Clothbound, \$28.95.

**Howard Dully and Charles Fleming.** *My Lobotomy.* New York: Crown-Random House, 2007. 288 pp. Paperback, \$13.95.

**Siri Hustvedt.** *The Shaking Woman, or a History of My Nerves.* New York: Henry Holt, 2009. 224 pp. Paperback, \$15.00.

**Alva Noë.** *Out of Our Heads: Why You Are Not Your Brain, and Other Lessons from the Biology of Consciousness.* New York: Hill and Wang-Farrar, Straus and Giroux, 2009. 232 pp. Paperback, \$15.00.

**Alix Kates Shulman.** *To Love What Is: A Marriage Transformed.* New York: Farrar, Straus and Giroux, 2008. 192 pp. Paperback, \$14.00.

**Jill Bolte Taylor.** *My Stroke of Insight: A Brain Scientist's Personal Journey.* Viking-Penguin, 2006. 224 pp. Paperback, \$15.00.

In 1960, twelve-year-old Howard Dully endured a transorbital lobotomy, involving the insertion of a surgical instrument through his eye socket to sever connections between his frontal cortex and the rest of his brain. In 1996, Jill Bolte Taylor, a brain anatomist, witnessed her own disorientation when she suffered a stroke one morning as she pre-

pared to go to work. In 2004, Alix Kates Shulman awoke in the middle of the night to find her husband unconscious after having fallen from the loft bed in the remote coastal cabin she used as a writing retreat. In 2006, Siri Hustvedt felt and watched her body convulse, her arms flail, and her skin discolor while she delivered a eulogy at a memorial for her father. These shocking experiences frightened Dully, Taylor, Shulman, and Hustvedt—but they also fascinated them—because they made philosophical or abstract questions about the connections between body, mind, self, and world physically and experientially concrete. All four have written *brain memoirs* that document their suffering and fascination, chronicles of the push-pull between their selves and their brains. In the case of all four writers, the relations between self and brain they chronicle aren't simply changed by brain disease or injury, but are continuously changing in reaction to altered brain function and the writers' living responses to their physiological conditions—including, crucially, writing about them.

Of course, there is a long tradition of autobiographical writing that chronicles mind-body relationships and their implications for selfhood, including the work of Augustine, Montaigne, Thomas De Quincey, Marcel Proust, and Virginia Woolf. Brain memoirs can be understood as the most recent incarnation of this longstanding tradition, though their explicit focus on the brain—and on the writer as organism—is more pointed than that of their predecessors. Like Siri Hustvedt's *The Shaking Woman* (2009), some of these recent memoirs chronicle the lived experience of their authors' "neurodiversity," including Kay Redfield Jamison's *An Unquiet Mind: A Memoir of Moods and Madness* (1995), Temple Grandin's *Thinking in Pictures* (1996) and *Emergence* (1996), Daniel Tammet's *Born on a Blue Day* (2007), Tim Page's *Parallel Play* (2009), and Lauren Slater's *Prozac Diary* (1999) and *Lying* (2001). Like Charles Dully's *My Lobotomy* (2007), some chronicle the aftermath or recovery from brain illness or injury, including Jill Bolte Taylor's *My Stroke of Insight* (2010) and Jean-Dominique Bauby's *The Diving Bell and the Butterfly* (1998). Like Alix Kates Shulman's *To Love What Is* (2009), some tell stories of caregivers or family living with a person suffering from brain injury or disease, including David B's *Epileptic* (2006), Jonathan Franzen's essay "My Father's Brain" (2001), and John Bayley's *Elegy for Iris* (1999). Others tell pharmacological or addiction stories about the capacity of drugs to alter body chemistry to shape the contours of a personality, including Caroline Knapp's *Drinking: A Love Story* (1997), Bill Clegg's *Portrait of an Addict as a Young Man* (2010), Elizabeth Wurtzel's *More, Now, Again* (2002), and Stephen Elliot's *The Adderall Diaries* (2009). Still

others investigate the distinctive features or idiosyncrasies of so-called “neurotypicals,” including Steven Johnson’s *Mind Wide Open* (2005) and Douglas Hofstadter’s *I Am a Strange Loop* (2008).

Brain memoirs do not let their writers—or readers—forget that they are organisms whose lives are shaped to a large degree by accidents of physiology, culture, family, and circumstance. They confront accidents by crafting a sense of agency that’s nuanced enough to account for what’s beyond their control. This is where their distinctive cultural work begins. Of course, brain memoirs come in a broad spectrum of forms and with a wide variety of agendas. Nonetheless, there are some common denominators. Broadly speaking, brain memoirs make at least five significant contributions to culture—in varying degrees for each particular memoir: (1) they enable their writers to gain a sense of agency or control in the face of the “accidents” that shape lives, including the accidents of genes, disease, or physical injury; (2) they offer much-needed solace and information to readers who suffer in ways similar to the writer as well as the loved ones and caretakers who support them; (3) they provide detailed, first-person accounts of neurological difference that have the potential to inform and influence brain research and clinical practice; (4) they renew and invigorate philosophical debates about mind and body, qualia, memory, and relationships between self and narrative; (5) they develop narrative strategies for representing the complexities of the minds and bodies of their authors.

Although the ostensible subject of brain memoirs is the writer’s particular subjective experience of an illness, difference, disorder, or injury, very often these memoirs become vehicles for large questions about the relationship between brain and self. Two classics in what’s becoming a crowded genre illustrate this nicely. In *An Unquiet Mind: A Memoir of Moods and Madness*, Kay Redfield Jamison acknowledges a problem with writing about her bipolar disorder that is central for any memoir that tells the story of the relation between brain, mind, and self: “I have become fundamentally and deeply skeptical that anyone who does not have this illness can truly understand it” (172). Similarly, in *Thinking in Pictures: My Life with Autism*, Temple Grandin asserts, “I am frustrated by the fact that some teachers and therapists still do not recognize the importance of sensory over sensibility. It must be difficult for them to imagine a totally different way of perceiving the world” (82).

If Jamison and Grandin have written memoirs that are classics in the genre, Oliver Sacks is its most influential progenitor. With his case

histories and autobiographical writing, Sacks created unlikely best sellers out of nonfiction neurological narratives. Since the publication of *The Man Who Mistook His Wife for a Hat* a quarter century ago, there have been rapid advances in brain science, due largely to brain scanning technologies like PET, CAT, and fMRI. During that period, numerous memoirists have emerged to tell stories about how their anomalous brains have shaped their lives and selves. These memoirists all share Sacks's penchant for using narrative to approximate the impossible: the revelation of another person's conscious experience. If I can riff on the title of Thomas Nagel's 1974 thought experiment, "What Is It Like to Be a Bat?," these memoirs ask, "What is it like to be autistic, epileptic, or 'locked in,' to suffer from profound amnesia, addiction, or Alzheimer's—or, for that matter, to be neurotypical?" Where many traditional memoirs take selfhood for granted, brain memoirs investigate how mind, brain, body, and culture interact to create or perform selfhood, and that investigation has social, scientific, and philosophical implications. In fact, recent brain memoirs may have a thing or two to teach neuroscientists about the self, and they certainly have quite a bit to teach the rest of us about the functional and theoretical promises and limits of current brain research.

Most of the neurological narratives under discussion here take the form of the quest—for new knowledge, understanding, healing, adaptation, and for reconciliation between scientific theory, medical practice, and the lived experience of patients (and writers). Hustvedt, who wrote *The Shaking Woman*, and Shulman, author of *To Love What Is*, are novelists, so it's no surprise that their accounts are highly literary in structure, care with language, allusions, and attention to matters of style and voice. At the same time, their aims are every bit as social and pedagogical as those of Dully in *My Lobotomy* and Taylor in *My Stroke of Insight*. All four writers recount their attempts to make sense of and to live with the profound changes to their lives that arise from disorders, injuries, and/or anomalies in the brain or the nervous system as a whole.

To write *My Lobotomy*, Dully tracked down the files of his surgeon Walter Freeman with the help of co-writer Charles Fleming. "The great mystery of my life was inside," he writes. "The question that haunted me for more than forty years was about to be answered" (x). According to the records, Dully's stepmother Lou fabricated a diagnostic history so that the stepson it seems she always hated would appear to be a candidate for Freeman's transorbital lobotomy. As a result, Dully is haunted by the question of who he would have been if his brain

had not been violated by the crude surgical procedure known as an “ice pick lobotomy.” He learns quite a bit from his file about exactly what happened and how. Toward the end of the book, he writes, “Ever since my lobotomy I’ve felt like a freak—ashamed. But . . . I know that my suffering is over. I know my lobotomy didn’t touch my soul. For the first time, I feel no shame. I am, at last, at peace” (256). Dully seems to use *soul* as a synonym for self, and while his story is convincing on the grounds of the peace he has found and the shame he has overcome, it does not offer persuasive evidence that his *self* is untouched by the lobotomy. In that sense, the “great mystery” of his life remains, though he learns to live with it.

Because Taylor is a brain anatomist, it may seem surprising that she is more pointedly concerned than Dully with the matters of the soul and self, or at least with spiritual dimensions of the self and their expression through the brain. Taylor awakens to “a sharp pain piercing [her] brain directly behind [her] left eye” and “stumble[s] into the world with the ambivalence of a wounded soldier” (37). Not yet fully conscious, she makes a characteristically idiosyncratic decision, to hop on her “cardio-glider” and start “jamming away to Shania Twain” (38). Then, it happened: “I felt a powerful and unusual sense of dissociation roll over me. I felt so peculiar that I questioned my well-being. Even though my thoughts seemed lucid, my body felt irregular. As I watched my hands and arms rocking forward and back, forward and back, in opposing synchrony with my torso, I felt strangely detached from my normal cognitive functions. It was as if the integrity of my mind/body connection had somehow become compromised” (38). This detachment persists and increases. Taylor “felt bizarre, as if [her] conscious mind was suspended somewhere between [her] normal reality and some esoteric space” (38). She becomes increasingly interested in this esoteric space because it offers her a view of the world she hasn’t seen before. Her book is primarily about her changed relationship to her brain and the implications of that change with regard to how we understand reality. She wants others to see the world the way she does after her stroke. In her words, “One of the greatest blessings I received as a result of this hemorrhage is that I had the chance to rejuvenate and strengthen my neurocircuits of innocence and inner joy” (139). Taylor attributes her new understanding and emotional fulfillment to her stroke.

In *To Love What Is*, Shulman offers a sharp and moving account of her search to learn how to live with her husband Scott after a brain injury that left his memory severely impaired, but other aspects

of his self intact. Shulman intercuts the story of Scott's accident and the life it creates for the couple with flashbacks to the history of this unusual marriage. The two were high school sweethearts, separated for decades before uniting in mid-life to form an unexpected bond for two people whose lives had diverged pretty sharply. From the beginning, Shulman felt a strong admiration and attraction to Scott's physicality, which she linked to his reserved, masculine, and trustworthy character. Her account makes it clear that memory and identity are not the same thing. Memory gives us a sense of autobiography, provides an ongoing narrative for the self, but Shulman lives with a man whose reserve, masculinity, and compassion outlive his capacity to remember what he's done, where he's been, and who he knows.

The quest Hustvedt recounts in *The Shaking Woman, or a History of My Nerves* is even more confounding (if slightly less alarming) than Dully's, Shulman's, or Taylor's because Hustvedt's symptoms are less clear-cut. Hustvedt is determined to find out what role her brain might play in her body's startling behavior: the sudden onset of a condition that caused her to convulse when she spoke in public (which she did often). The first incident occurred at a memorial service for her father:

I looked out at the fifty or so friends and colleagues of my father's who had gathered around the memorial Norway spruce, launched into my first sentence, and began to shudder violently from the neck down. My arms flapped. My knees knocked. I shook as if I were having a seizure. Weirdly, my voice wasn't affected. It didn't change at all. Astounded by what was happening to me and terrified that I would fall over, I managed to keep my balance and continue, despite the fact that the cards in my hands were flying back and forth in front of me. When the speech ended, the shaking stopped. I looked down at my legs. They had turned a deep red with a bluish cast. (3)

With that glance at her deep red legs, Hustvedt begins her quest to understand what her body did that day—and on so many subsequent days when she spoke in public. As she writes, "I decided to go in search of the shaking woman" (7).

In general, the quests these memoirs chronicle prompt their authors to confront philosophical questions about the relationship between brain, body, self, and culture on just about every page. The insights they offer about these relationships, however, tend to be local and personal, rather than grand or totalizing.

### Are You Your Brain?

While neuroscience has advanced rapidly in recent years, enabling recovery or therapy for many people suffering from brain injuries or disorders, the hype surrounding these advances has left most of their philosophical implications overlooked, underlooked, exaggerated, or distorted. Early on, Jamison and Grandin described particular incarnations of a general problem confronted by philosophers of mind for centuries and, more recently, by neurobiologists and cognitive scientists: the impossibility of gaining first-hand knowledge of what neurobiologist Antonio Damasio has called a “private, first-person phenomenon.”<sup>1</sup> Damasio is describing a problem for philosophy and for empirical laboratory research. He and colleagues like Gerald Edelman, Jaak Panksepp, and Mark Solms are busy devising methods for integrating the examination of subjective experience into brain research and theory. But there’s a lot they don’t know yet. If you listen to the hype—in the press and also in scientific publications—you might think philosophical questions about the relationship between a person’s body, brain, mind, and self have been cracked by laboratory science and that we are on the verge of understanding our biology so well that the philosophical questions have become quaint historical forerunners to the hard sciences rapidly rendering them moot. But the full complexity of the relationships between the body, the brain it contains, the mind generated by it, and the self that feels and acts in the world has not been revealed by fMRI or PET scans. The nascent neuroscience of the self has generated many questions, much promising data, fluctuating diagnoses, and a host of fascinating (and sometimes almost fantastical) case histories, but its fledgling answers tend to be very local or highly theoretical.<sup>2</sup>

For decades, Damasio has been examining the experience of his patients through the lens of philosophical questions about consciousness, emotion, and cognition. His newest book, *Self Comes to Mind: Constructing the Conscious Brain* (2010), is in many ways a cap and a reflection on his trilogy of bestsellers on the topic: *Descartes’ Error: Emotion, Reason, and the Human Brain* (1994), *The Feeling of What Happens: Body and Emotion in the Making of Consciousness* (1999), and *Looking for Spinoza: Joy, Sorrow, and the Human Brain* (2003). The titles of all these books reveal a bias toward thinking of the brain as the generator of self, and this bias is the focus of philosopher Alva Noë’s critique of neuroscience in *Out of Our Heads: Why You Are Not Your Brain and Other Lessons from the Biology of Consciousness* (2010). Damasio’s



and Noë's books represent the best of two camps in a debate that's beginning to rage about neuroscience's capacity to understand the self. Noë's subtitle offers a preview of his arguments. He's concerned about the neuroscience hype. He argues that consciousness is "more like dancing than it is like digestion" (xii). It is, he writes, "something we do or make. Better: it is something we achieve" (xii). He does not believe the feeling of being a living self can be explained "in neural terms alone" (xii). We are whole bodies. We are social organisms with life histories who occupy complex environments. Noë is convinced that the neuroscience hype has taken the brain out of its contexts and imagined it thriving in a vat—as in *The Matrix* or any number of philosophical thought experiments—to convince us that our brains contain the whole story of selfhood.

Damasio may well be one of the culprits behind the hype Noë bemoans, though it's difficult to know, because Noë doesn't cite Damasio's growing number of books on the topic. Nor does Damasio address Noë's critique directly in *Self Comes to Mind*. In this book, Damasio recapitulates his earlier theories even as he admits that he's "grown dissatisfied with [his] account of the problem" of consciousness and that he's changed his mind "on two issues in particular: the origin and nature of feelings and the mechanisms behind the construction of the self" (6). Damasio now believes that feelings are even more important to the generation of conscious experience than he thought previously and that neural mechanisms in the brain stem are more important in the process of producing these feelings. There is something rhetorically tricky about the assertion that Damasio has changed his mind because his argument confirms and elevates the status of mechanisms that have always been his favorite topics: feelings (as opposed to emotions), the proto-self (the brain's preconscious "map" of the organism's body, or "internal milieu"), and core consciousness (the feeling of being present and alive in an environment full of objects at any given moment) (18, 42). He does, however, offer an additional category for consideration: primordial feelings, an organism's barely or nearly felt sense of its body's interior. Although the outlines of his theory have not changed much, his hypotheses about the brain physiology that contributes to forming the self have evolved.

In many ways Damasio's and Noë's books complement each other nicely. Damasio's is full of concrete detail about physiology and clinical observations, examined and interpreted through the lens of philosophical questions that are sometimes addressed hastily. Noë is careful with his philosophical arguments, but as hasty with science as

Damasio is with philosophy. It's unfortunate that these two thinkers do not address or cite each other and that they don't find a middle ground in terms of methodology. If they did, their differences would likely be revealed as matters of emphasis and rhetoric more than belief or conviction. In fact, both writers are really asking, "What roles do our brains play in making us who we are?" and "How do particular brain functions, regions, and systems contribute to the shaping and development of identity, personality, and disposition?" These are more nuanced questions than "Are you your brain?" Damasio, the neurologist, emphasizes physiology (the body as a whole, not just the brain). Noë, the philosopher, emphasizes the environmental and social contexts of an organism's brain and body.

Brain memoirs are already asking the more nuanced questions. Nearly all of them are concerned with how our brains contribute to *particular* aspects of self in the context of a life and an environment. The experience of the memoirists, navigating science and medicine in order to craft lives (and books) that help them cope with their brains, leads to an organic acceptance that we do not know much about the relationship between brain and self. These books offer the theorists a lesson in humility: the neuroscience of the self should be approached only hypothetically, with an emphasis on the experiences of the organisms it studies. Too often, as Noë's book makes clear, these questions are addressed prematurely and reductively, overlooking what we don't know or pretending we know more than we do.<sup>3</sup> For the memoirists, the questions, the hypothetical data, the fluctuating diagnoses, and the grand theories provide a new context in which to explore ancient questions about selfhood. Dully's lobotomy, Hustvedt's convulsions, Shulman's husband's accident, and Taylor's stroke all prompt them to go searching for the relationship between the brain and the self—to seek understanding that will help them live with their altered circumstances. These writers, apropos of Noë, may not *be* their brains, but their brains shape their experiences in ways that are fundamental and undeniable.

#### How Do Brain Memoirists Understand the Lived Relations between Brain and Self?

Living with uncertainty is a fundamental theme in brain memoirs, a theme about which the memoirists have something to teach the scientists who study brains and the doctors who treat them. It

seems inevitable that the writer's lived experience will sometimes contradict the advice, doctrine, treatment, and data offered by professionals. The contradictions tend to bewilder patients, even those with the wherewithal to write memoirs at least partly designed to reveal the contradictions and improve the science of medicine in ways that will help future patients.

Dully's neurosurgeon, Dr. Walter Freeman, is the most egregious physician portrayed in any of these memoirs. He was an enthusiastic proponent of the transorbital lobotomy, a procedure so brutal it was sometimes performed with an ice pick. The results were highly variable, from death to miniscule changes in behavior. Freeman's notes about Dully are detailed and frank, so much that they reveal his stepmother Lou's manipulation of his "symptoms" and Freeman's doubts about his young patient's candidacy and his outcome. He learns that Lou visited six psychiatrists before finding Freeman; four of these diagnosed *her* as the problem. He learns that Freeman was concerned about his professional status and that his lobotomies had already fallen out of favor by the time he treated Dully. In short, he learns quite a bit, but he does not get his central question answered. He does not learn who he'd have been with a different brain. He doesn't even learn how dramatically his brain may have been altered. At this stage in medical history, nobody can tell him that.

The discoveries Siri Hustvedt makes in *The Shaking Woman* are also about adaptation and living with uncertainty more than with hard facts or cures. When Hustvedt goes looking for the woman who shakes, she consults neurologists and psychiatrists, reads philosophy and the history of medicine, and seeks to understand the relationship between mind and body by looking at fMRI images of her brain and practicing biofeedback techniques. In the process, she manages to make philosophy, neurology, and history seem like the stuff of mystery novels. Her book is a page-turner. As in so many brain memoirs, Hustvedt's physicians are flummoxed. They disagree with and contradict each other. Some offer answers that seem too easy; others deny the reality of her experience altogether. Finally, she gets a drug in place of a diagnosis. Neurology, psychology, and psychoanalysis can't explain why Hustvedt shakes, but Propanolol (or the placebo effect) forestalls the shaking. The chemistry of the shaking woman's brain is at play in making her who she is, but how and why remain vague.

In the absence of answers, Hustvedt finds intellectual stimulation and emotional solace in the philosophical implications of contemporary neuroscience. Her reading ranges freely over William James and Antonio

Damasio, Maurice Merleau-Ponty and Jaak Panksepp. The arc of her narrative traces the development of her relationship to the shaking. Early on, she describes her condition almost as a visitation: "It appeared that some unknown force had suddenly taken over my body and decided I needed a good, sustained jolting" (4). Sentiments like this are common in autobiographical works about the brain, which tend to suggest an implicit, though unstable, dualism. They characterize the brain as an entity or force that is both part of and separate from the self or organism writing the story. Illness tends to throw this unstable dualism into relief, to make apparent a kind of alienation between brain and self that haunts everyday life. In Hustvedt's words, "Every sickness has an alien quality, a feeling of invasion and loss of control that is evident in the language we use about it" (6). The condition feels alien partly because its onset is so sudden and partly because it seems willful. But the will in question doesn't feel like her own conscious will. If Hustvedt were writing in the nineteenth century, or if she were a devout Christian, she might see this will as either divine or evil. From Hustvedt's secular position, it seems as though there is a hidden force with a will of its own somewhere inside her body or brain. A friend who witnesses one of her episodes reinforces the split when she tells Hustvedt, "it [was] like watching a doctor and a patient in the same body" (30). In fact, Hustvedt takes on this dual role as doctor and patient, taking a far more active role in her search for a diagnosis than the medical establishment generally encourages or even allows.

Toward the end of the book, still without a firm diagnosis, Hustvedt asks, "Can I say that the shaking woman is a repeatedly activated pattern of firing neurons and stress hormones released in an involuntary response, which is then dampened as I keep my cool, continue to talk, convinced that I'm not really in any danger? Is that all there is to the story?" (116). If the answers to these questions are *yes*, then the origins of the shaking are beyond the will, arising from the body's ongoing, involuntary processes that maintain homeostasis and keep our systems operating. Keeping her cool, however, is a willful act whereby Hustvedt dampens the impulse to resist or fight what's happening to her. It feels to her as if keeping her cool may have a therapeutic effect, somehow shifting the neuronal and hormonal patterns that drive her body to convulse, her arms to flail, and her legs to turn a deep red. Hustvedt is speculating here. Her "cool" is not a medically recognized treatment. But it is one of the keys to the philosophical questions her book explores, questions about how

the conscious and the unconscious impinge on each other as they respond to objects in an organism's world—and how a sense of self is produced in the process.

Damasio could almost be describing Hustvedt's relationship to her shaking body when he argues that we must understand two integrated aspects of self in order to understand biology's role in the formation of identity. He calls these the "self-as-object" and the "self-as-subject" (8, 9). The shaking woman is Hustvedt's object self; the tireless diagnostician is her subject self. According to Damasio, the object self is "a dynamic collection of integrated neural processes, centered on the representation of the living body, that finds expression in a dynamic collection of integrated mental processes" (9). By contrast, "the self-as-subject, as knower, as the 'I,' is a more elusive presence" (9). In other words, research is beginning to reveal how the brain maps the body, making an "object self" out of it, for the purpose of maintaining the preconscious activities necessary for a body to live.

The subject self is another issue, however. In biological terms, the subject self is "dispersed," meaning that it involves a vast array of brain processes, cognitive traits, and mental functions: perception, memory, thought, emotion, etc. (9). Brain research is not currently in a position to imagine offering an account of the physiology involved in Hustvedt's evolving feelings and knowledge about her condition, not to mention the ways that condition changes her sense of self as she evolves into "the shaking woman." Damasio would like his readers to "imagine that the self-as-subject-and-knower is stacked, so to speak, on top of the self-as-object, as an additional layer of neural processes that gives rise to yet another layer of mental processing" (9–10). This layering, he says, reveals that "there is no dichotomy between self-as-object and self-as-knower; there is, rather, a continuity and progression" (10). So the shaking someone may be a product of what Damasio calls *stacking*, but of course that's a metaphor, not a concrete description of physiology. Often, metaphors mask the limits of knowledge in science. A memoir like Hustvedt's challenges brain science to acknowledge its current limitations. Like Enlightenment science, today's neuroscience sometimes represents itself on the verge of offering the key to all knowledge—something like Causabon's "Key to all Mythologies" in George Eliot's *Middlemarch*. But if neither the practitioners nor the theorists can explain Hustvedt's shaking or tell Dully just how his transorbital lobotomy changed his personality, then those keys are far from unlocking the answers philosophers have been seeking for millennia.

Noë, the philosopher, offers a different window onto Hustvedt's shaking and Dully's lobotomy. He proposes "that the brain's job is that of facilitating a dynamic pattern of interaction among brain, body, and world. Experience is enacted by conscious beings with the help of the world" (47). The implication is that we should take Hustvedt's grief (and the collective grief of the audience for her eulogy) and the rage in Dully's family (and the abuse it suggests) more seriously as actors in the making of these writers' suffering and searching selves. It seems to me that Damasio believes something very similar, but Noë is making the point that emphasis matters. It's fine for Damasio to believe that body and world are integral to the making of consciousness, but if he spends hundreds of pages on neural mechanisms and just a few paragraphs on the objects that comprise an organism's world, he contributes to the misleading hype that we are our brains, end of story. Disciplinary divides and rhetoric conceal underlying agreements about brain, body, self, and culture—agreements that might offer memoirists like Hustvedt and Dully more insight, more effective treatments, and more humane medical practices if they were to become the focus of the theorists' work.

Because no general theory can encompass the particular experience of an individual, brain memoirists have to find a narrative form that can capture and sustain the complexities of the questions generated by brain anomalies whose symptoms alter identity. Shulman's *To Love What Is*, the testimony of a caretaker rather than a patient, is an illuminating example of the necessity of devising a form to meet the demands of the problem at hand. Her narrative is layered, with alternating descriptions of a youthful fling, a midlife reunion and enduring commitment, Scott's devastating accident, and after that, the couple's learning how to live and love in his eternal present. The layers give the voice a developmental quality. The naive young lover becomes the outspoken feminist novelist who becomes the philosophically-minded caretaker determined to protect her own fierce independence and Scott's quality of life. The book is tough and tender. It is wise in its response to what many would call tragedy and brilliant in its ability to sift through the uncertain knowledge of brain science to develop a set of strategies tailored to living with, rather than diagnosing, Scott's damaged brain.

Shulman isn't suggesting that Scott's injury hasn't changed him, just that it hasn't changed him entirely. The degree to which he's changed varies from day to day, hour to hour, and sometimes minute to minute. Shortly after the accident, he exhibits what is to be the

most uncharacteristic behavior that will become, off and on, a new dimension of his personality:

The dignified, courtly man I love has emerged from his enforced silence a loquacious stranger—sometimes a clown, full of wild flights of wordplay that keep Heather and Norm and me howling with laughter, sometimes a garrulous, nonsensical, even dirty old man hitting on the nurses. *Fluent aphasia* is the name the doctors give to this uncontrollable verbal pandemonium, a result of damage to the brain's speech centers, by which, in place of the elusive, sought-after words, the lips spew forth a circuitous approximation that usually sounds like babble but sometimes hints at wisdom. Are the myriad substitute words arbitrary or telling? Since aphasia, of both the fluent and non-fluent varieties, is caused by bodily injury or disease and often disappears with time, it would seem purely physical, not psychological. Yet overlaying my modest husband there appears to be another man with multiple alien personalities—now outgoing and entertaining, now authoritative and managerial—and all of them named Scott York. Can his injury have transformed his very self, stricken deep into his identity? Or revealed a buried self I never knew? (33)

Shulman tells us what can be known—that aphasia is associated with damage to “the brain's speech centers.” But from there, she offers questions that cannot be answered with what is known about the brain mechanisms involved with language. Like so many brain memoirists, Shulman offers narrative in the absence of answers.

Toward the end of the book, Shulman describes a calculated risk she decided to take: accepting an offer from friends Heather and Norm to accompany them on a trip to Tuscany. At first, Scott is disoriented, asking repeatedly if they are in “The *real* Italy? The *real* Tuscany?” When they arrive at their villa, where the driveway is lined with blooming acacia trees, Scott's perspective shifts: “‘Will you just look at that yellow!’ cries Scott. . . . He grins with incredulous joy. Beginning with the Cleveland arboretum, where he first kissed me in 1950 beneath the spreading branches of that Ohio buckeye, and on to the renowned botanical gardens of Miami, Sydney, Honolulu, Tucson, and Brooklyn . . . to the famous bo trees and banyans of India, Scott and I, ardent arbor enthusiasts, have basked in and under distinguished trees” (135).

Scott's response to the acacia trees, like so many of his sensory responses, is inflected with emotions both familiar and characteristic from the time before his accident. Upon their return from New York, Scott tells his wife that they "forgot to bring something home from Tuscany." When she asks him what that is, he responds, "A yellow tree!" (138). Shulman's risk has paid off. She has given Scott an experience that becomes a new memory, even if it's a halting and unstable one. Scott doesn't recover substantially more than this; in fact, over time, his memory and health decline. But he does make some successful art; he does express love and rage, disappointment and joy.

Shulman follows the narration of the Tuscany trip with some reflections on the science of memory. "Little is known," she writes, "about the way information in your short term memory . . . is converted into long-term memory for retrieval whenever you want it" (139). She goes on to explain the well-accepted hypotheses that emotion is crucial to the conversion; that the hippocampi, "important structures deep inside the temporal lobes," are crucial to the process; that "experiments on slugs, rats, and monkeys . . . have established connections between memory retention and, variously, a certain gene, a particular enzyme, REM sleep patterns, a molecular pathway, a habit state" (140). Ultimately, though, these are fragments of a process that still eludes science. In Shulman's words, again, "how memories are actually laid down and stored in the brain—what the process of becoming electrochemically hardwired consists of—remains a mystery" (140). There is no doubt that memory is crucial to the creation of the fully realized autobiographical selves most of us take for granted. There is little doubt that the experiments Shulman lists have identified fundamental aspects of the process by which long-term memory enables us to experience autobiographical selves. But Scott's accident puts Shulman in the position of experiencing, day-to-day, that memory is not all there is to identity.

In *My Stroke of Insight*, Taylor comes to understand her own identity as an organism to be a multifarious enterprise that sounds a lot like Damasio's "dispersed" self (9): "I still experience the collective of myself as a single entity with a single mind. I do believe that the consciousness we exhibit is the collective consciousness of whatever cells are functioning, and that both of our hemispheres complement one another as they create a single seamless perception of the world" (137). Without attempting a comprehensive theory, Taylor suggests that the cellular self is a local expression of a metaphysical reality. With her interest in esoteric aspects of consciousness, Taylor verges on the



mystical much more than Hustvedt, Shulman, or Dully.<sup>4</sup> In her account of her stroke, this interest only intensifies as the symptoms become more severe, until she finally loses consciousness and with it the ability to reflect. She notices that her movements “are no longer fluid,” that they are “jerky”; she gains an awareness of “automatic body responses”; she feels “momentarily privy to a precise and experiential understanding of how hard the fifty trillion cells in [her] brain and body were working in perfect unison to maintain the flexibility and integrity of [her] physical form” (39); she showers and reels from the “roar of the water” (40); she feels increasingly isolated, losing awareness of “the sensations outside of [her]” (41). The more disoriented she becomes, the more she feels a “growing sense of peace” (41). Her amygdala, she surmises, had not “reacted with alarm” (41), and she feels fortunate about this. She loses awareness of physical reality, even as she tries to dial her phone for help. But her sheer interest in her experience outweighs alarm. Taylor “felt truly at one with [her] body as a complex construction of living, thriving organisms” (43).

Two aspects of this observation are particularly striking. First, the optimism that makes Taylor’s book distinctive—and probably also what helped her publisher gain the self-help market. She’s had a stroke and she’s happy about the insight she’s gained from the experience. Second, her use of the plural to describe herself, as a conglomerate of “living, thriving organisms” contains a hidden thesis. It would be easy to celebrate Taylor’s optimism and stop there, but her argument about the plurality of organisms and systems that make us feel like singular, unified selves is just as significant. Her book is explicitly pedagogical, as was the talk she gave at the TED conference when she first broke her story, a talk that went viral, led to Taylor’s minor celebrity, and played no small part in her book contract. While her upbeat response to her stroke has received a great deal of attention, her more philosophical point about the neurology of self threatens to go unnoticed.<sup>5</sup>

The neurological experience that motivates brain memoirists to write ensures that they cannot take selfhood for granted, just as the research of a neuroscientist or philosopher of mind cannot. As a result, the memoirists and the theorists draw some consistent conclusions, many of which run against the grain of widespread cultural assumptions and of popular accounts of brain research. The self, they suggest, is by no means a single entity. It’s an experience of unity that emerges from conglomerates of neurological, physiological, mental, familial, and social elements. The complexity of this conglomerate is humbling and

awe-inspiring. While hasty or reductive claims that we're on the brink of understanding how the brain generates selfhood abound, the real implication of the last few decades of brain research is the spectacular complexity of the brain's collaborative role in generating self.

### Writing and the Making of Self

In his essay "The Stream of Consciousness," William James argues that "the object before the mind always has a 'Fringe'."<sup>6</sup> In other words, we are conscious of the objects we're paying attention to—for these memoirists, the relations between their brains, bodies, selves, and worlds—but our minds also vaguely sense meanings and associations of which we're not quite conscious. Writing, these memoirists suggest, shifts this fringe into the center of attention. Through the process of putting words to page, we become conscious of what we didn't quite know beforehand. James argues that "a good third of psychic life consists in these rapid premonitory perspective views of schemes of thought not yet articulate."<sup>7</sup> The writing of a brain memoir could be seen as an exercise in premonitory thinking, living, and being, ushering not quite felt aspects of bodily experience into awareness.

Of course, as James also notes, the making of art is a selective process. Even artists whose intention is to represent something like James's fringe—the surrealists, for example—do so by a careful process of selection and arrangement of the tools of their medium. In James's words, "The artist notoriously selects his items, rejecting all tones, colors, shapes, which do not harmonize with each other and with the main purpose of his work. That unity, harmony, 'convergence of characters,' . . . is wholly due to elimination. Any natural subject will do, if the artist has wit enough to pounce upon some one feature of it as characteristic, and suppress all merely accidental items which do not harmonize with this."<sup>8</sup> It's remarkable how often brain memoirists articulate these two elements of composition—bringing the fringe into awareness and synthesizing new thoughts—as fundamental to integrating their changed neurological experience into their sense of their own identities. Shulman "hadn't expected to write about so private and raw a subject" (115) but decided to do so because "there was the possibility that writing about it could help me understand it" (116). She writes her way through a quest to learn to live with her husband Scott in the continuous present his damaged memory creates for him. Hustvedt articulates the daily process of writing as a vehicle

for synthesizing her sense of self with the “alien” force in her body that makes her shake (6). Dully comes to peace with his lobotomy by way of his research and writing. Through writing about her stroke, Taylor comes to the conclusion that “this story-teller portion of our left mind’s language center is specifically designed to make sense of the world outside us, based on minimal amounts of information” (143). Taylor finds her own hasty “left mind” conclusions “comical” at first, but she comes to a realization that speaks to the role of writing and the evolution of identity dramatized in many brain memoirs: “It has been extremely important that I retain the understanding that my left brain is doing the best job it can with the information it has to work with. I need to remember, however, that there are enormous gaps between what I know and what I think I know. I learned that I need to be very wary of my story-teller’s potential for stirring up drama and trauma” (144). The gap between “what I know” and “what I think I know” is vivid in all these brain memoirs. In addition to offering the rest of us some lessons about living with uncertainty, this gap—which sounds a lot like James’s fringe—signals the potential for writing to mediate the accidents and agency involved in the making of identity.

Shulman describes the process of writing as mediation with characteristic grace: “So it happens that at nine o’clock each morning I banish the real Scott in order to entertain the virtual one, who stays with me on the page until two, when the real one opens our door, exclaiming, ‘Look who it is! It’s my beautiful wife!’ and hugs me like a returning warrior” (116). Her juxtaposition of “the real Scott” and “the virtual one” is incisive: it speaks to *how* memoir might generate agency. By creating a virtual portrait of Scott, a companion to the self-portrait that emerges from Shulman’s compassionate and articulate voice, she recreates the life with which she and Scott are struggling. In the process, she reorients herself in relation to that life. “Writing,” she continues, “takes me out of my sometimes beleaguered self into the trancelike realm of alpha waves, where, like Scott, I live in the moment” (165). The act of writing and the habits of mind it requires shape Shulman’s consciousness profoundly. She describes her time in the “alpha waves” as a therapeutic practice that enables her to live: “With five focused hours a day of aesthetic relief, I have my life again, with enough satisfaction to carry me through the entire day, and in the evenings back to the world, no longer alien” (165). The word “trancelike” suggests a liminal state between the conscious and the unconscious, one that, like dreams, promises to put the two aspects of mind into closer contact than they are under ordinary cir-

cumstances. The phrase “in the moment” suggests that writing involves the suspension of full-scale autobiographical awareness in favor of what Damasio calls alternately “core consciousness” and “core self,” whereby an organism interacts with—and is changed by—the objects perceived in its immediate environment. The ironies here are productive: to achieve agency through writing, Shulman suspends conscious intention; to reflect on the story of her life with Scott, she suspends autobiographical awareness.

Analogously, Hustvedt becomes the shaking woman through writing: she articulates the daily process of writing as a vehicle for synthesizing her sense of self with the “alien” force in her body that makes her shake. “[W]hen I’m writing,” she says, “much is generated unconsciously”:

I feel beneath my words a preconscious world from which I draw them, thoughts not yet articulated but potentially there, and when I find them, I believe in their rightness or wrongness. Yes, that’s what I wanted to say. Against what do I measure this? It is not *outside* me. I don’t have some externalized notion of the perfect sentence that best expresses what I want to say. The knowledge lives inside me, and yet, isn’t that verbal interior made from the exterior, from all the books I’ve read, the conversations I’ve had and their mnemonic traces? (88)

Again, the preconscious world Hustvedt relies on—which she calls “that half-remembered underground” (88)—sounds an awful lot like James’s fringe. Like Shulman, she draws on what’s unconscious to craft a sense of control—or agency—through writing. She understands that “the exterior” is part of the equation, too, the social forces shaping her internal sense of self: “all the books [she’s] read, the conversations [she’s] had” (88). And she makes it clear that the elimination and selection James recognizes as fundamental to the process of turning perceptual objects into art are integral to the process of using words to mediate the relationship between accident and agency. Writing foregrounds the dynamic interplay between fringe and intention, and this is why the brain memoir can be such a powerful tool for people forced by neurological circumstances into crafting an identity. Through writing they find ways to accommodate changes in their brains and bodies that can’t be ignored. The memoir is a chronicle of the intricate entanglements of brain, body, self, and world that are so complex they defy the most advanced technologies of neuroscience and our cognitive capacities. If

brain memoirs have a thesis, it's this: the complicated interconnections of brain, body, self, and world require us to learn how to think, how to conduct research, how to write, and how to live in the world of Taylor's gaps, Shulman's alpha waves, Hustvedt's "half-remembered underground," James's fringe. These writers are organisms who have learned the wisdom of epistemological humility by making their brains and bodies the objects of their narrative attention.

## NOTES

1. Damasio, *The Feeling of What Happens*, 12.

2. An extensive body of literature on the neurology of the self has emerged in recent years. In addition to the work of Damasio and Noë, some of the most influential of these texts include: Ansermet and Magistretti, *The Biology of Freedom*; Broks, *Into the Silent Land*; Edelman, *Wider than the Sky*; Edelman and Tononi, *A Universe of Consciousness*; Gazzaniga, *Human*; Keenan, *The Face in the Mirror*; LeDoux, *The Synaptic Self*; Panksepp, *Affective Neuroscience*; Ramachandran, *The Tell-Tale Brain*; Ramachandran and Blakeslee, *Phantoms in the Brain*; and Solms and Turnbull, *The Brain and the Inner World*.

3. There is a growing critique of this neuroscientific reductionism emerging from the social sciences. The following are among the strongest of these critiques: Johnson, "How Do You Know Unless You Look?": Brain Imaging, Biopower, and Practical Neuroscience"; Jordan-Young, *Brain Storm: The Flaws in the Science of Sex Research*; Martin, "Mind-Body Problems"; Pitts-Taylor, "Social Brains, Embodiment, and Neurointeractionism"; and, from within the sciences, Roy, "Asking Different Questions: Feminist Practices for the Natural Sciences."

4. In that sense, her perspective resounds with William James's lectures "On Mysticism," from *Varieties of Religious Experience*, where he insists that subjective accounts of mystical experience needed to be taken seriously on their own terms, and with the work of proponents of drug-induced psychedelic experience like Aldous Huxley, Timothy Leary, and (more recently) Daniel Pinchbeck.

5. To view Taylor's TED talk, see [http://www.ted.com/talks/jill\\_bolte\\_taylor\\_s\\_powerful\\_stroke\\_of\\_insight.html](http://www.ted.com/talks/jill_bolte_taylor_s_powerful_stroke_of_insight.html)

6. James, "The Stream of Consciousness," 30.

7. *Ibid.*, 31.

8. *Ibid.*, 40.

## ADDITIONAL RECOMMENDED BRAIN MEMOIRS

Patrick Cockburn and Henry Cockburn. *Henry's Demons: Living with Schizophrenia, a Father and Son's Story*. New York: Scribner, 2011.

Alice Weaver Flaherty. *The Midnight Disease: The Drive to Write, Writer's Block, and the Creative Brain*. New York: Houghton Mifflin, 2004.

Temple Grandin. *Thinking in Pictures: My Life with Autism*, Expanded Edition. New York: Vintage, 2010.

Lynn Greenberg. *The Body Broken: A Memoir*. New York: Random House, 2009.

Kay Redfield Jamison. *An Unquiet Mind: A Memoir of Moods and Madness*. New York: Vintage, 1997.

- Heather Sellers. *You Don't Look Like Anyone I Know: A True Story of Family, Face-blindness, and Forgiveness*. New York: Riverhead Books, 2010.
- Daniel Tammet. *Born on a Blue Day: A Memoir*. New York: Free Press, 2007.
- Melanie Thernstrom. *The Pain Chronicles: Cures, Myths, Mysteries, Prayers, Diaries, Brain Scans, Healing, and the Science of Suffering*. New York: Farrar, Straus & Giroux, 2010.
- Mark Vonnegut. *Just Like Someone with Mental Illness Only More So: A Memoir*. New York: Delacorte Press, 2010.

## BIBLIOGRAPHY

- Ansermet, Francois and Pierre Magistretti. *The Biology of Freedom: Neural Plasticity, Experience, and the Unconscious*. Translated by Susan Fairfield. New York: Other Press, 2007.
- B., David. *Epileptic*. New York: Pantheon, 2006.
- Bailey, John. *Elegy for Iris*. New York: Picador, 1999.
- Bauby, Jean-Dominique. *The Diving Bell and the Butterfly*. Translated by Jeremy Leggatt. New York: Vintage, 1998.
- Broks, Paul. *Into the Silent Land: Travels in Neuropsychology*. New York: Atlantic Monthly Press, 2004.
- Clegg, Bill. *Portrait of an Addict as a Young Man*. New York: Little Brown and Company, 2010.
- Damasio, Antonio. *Descartes' Error: Emotion, Reason, and the Human Brain*. New York: Penguin, 2005.
- . *The Feeling of What Happens: Body and Emotion in the Making of Consciousness*. New York: Mariner Books, 2000.
- . *Looking for Spinoza: Joy, Sorrow, and the Feeling Brain*. New York: Mariner Books, 2003.
- Elliot, Stephen. *The Adderall Diaries*. New York: Graywolf Press, 2009.
- Edelman, Gerald M. *Wider than the Sky: The Phenomenal Gift of Consciousness*. New Haven: Yale University Press, 2005.
- Edelman, Gerald M. and Giulio Tononi. *A Universe of Consciousness: How Matter Becomes Imagination*. New York: Basic Books, 2001.
- Eliot, George. *Middlemarch*. Edited by Bert G. Hornbach. New York: Norton, 1977.
- Franzen, Jonathan. "My Father's Brain." *The New Yorker*. September 10, 2001, 80–91.
- Gazzaniga, Michael. *Human: The Science Behind What Makes Us Human*. New York: Harper Perennial, 2009.
- Grandin, Temple. *Thinking in Pictures: My Life with Autism, Exp. Edition*. New York: Vintage, 2010.
- Grandin, Temple and Margaret M. Scariano. *Emergence: Labeled Autistic*. Novato, CA: Warner Books, 1986.
- Hofstadter, Douglas. *I Am a Strange Loop*. New York: Basic Books, 2008.
- Huxley, Aldous. *The Doors of Perception*. New York: Harper Perennial, 2009.
- James, William. "The Stream of Consciousness." In *Psychology: The Briefer Course*. Mineola, NY: Dover Books, 2001: 18–42.
- . *Varieties of Religious Experience*. In *Writings: 1902–1910*. New York: Library of America, 1988: 1–478.
- Kay Redfield Jamison. *An Unquiet Mind: A Memoir of Moods and Madness*. New York: Vintage, 1997.
- Johnson, Davi. "'How Do You Know Unless You Look?': Brain Imaging, Biopower, and Practical Neuroscience." *Journal of Medical Humanities* 29, no. 33 (2008): 147–161.

- Johnson, Steven. *Mind Wide Open: Your Brain and the Neuroscience of Everyday Life*. New York: Scribner, 2005.
- Jordan-Young, Rebecca M. *Brain Storm: The Flaws in the Science of Sex Research*. Cambridge, MA: Harvard University Press, 2010.
- Keenan, Julian. *The Face in the Mirror: The Origins of Consciousness*. New York: Harper Collins, 2003.
- Knapp, Caroline. *Drinking: A Love Story*. New York: Dial Press, 1997.
- Leary, Timothy. *The Psychedelic Experience: A Manual Based on the Tibetan Book of the Dead*. New York: Citadel Press, 1992.
- LeDoux, Joseph. *The Synaptic Self: How Our Brains Become Who We Are*. New York: Penguin, 2003.
- Martin, Emily. "Mind-Body Problems." *American Ethnologist* 27, no. 3 (August 2000): 569–590.
- Nagel, Thomas. "What Is It Like to Be a Bat?" *The Philosophical Review* 83, no. 4 (October 1974): 435–450.
- Page, Tim. *Parallel Play: Growing Up with Undiagnosed Asperger's*. New York: Doubleday, 2009.
- Panksepp, Jaak. *Affective Neuroscience: The Foundations of Human and Animal Emotions*. New York: Oxford University Press, 1998.
- Pinchbeck, Daniel. *Breaking Open the Head: A Psychedelic Journey into the Heart of Contemporary Shamanism*. New York: Broadway Books, 2003.
- Pitts-Taylor, Victoria. "Social Brains, Embodiment, and Neurointeractionism." Forthcoming in *The Body Handbook*, edited by Bryan S. Turner. New York: Routledge, 2012.
- Ramachandran, V. S. *The Tell-Tale Brain: A Neuroscientist's Quest for What Makes Us Human*. New York: Norton, 2011.
- Ramachandran, V. S. and Sandra Blakeslee. *Phantoms in the Brain: Probing the Mysteries of the Human Mind*. New York: Harper Perennial, 1999.
- Roy, Deboleena. "Asking Different Questions: Feminist Practices for the Natural Sciences." *Hypatia* 23, no. 4 (November 2008): 135–157.
- Sacks, Oliver. *The Man Who Mistook His Wife for a Hat: And Other Clinical Tales*. 1985. New York: Simon and Schuster, 1998.
- Slater, Lauren. *Lying: A Metaphorical Memoir*. New York: Penguin, 2001.
- . *Prozac Diary*. New York: Penguin, 1999.
- Solms, Mark and Oliver Turnbull. *The Brain and the Inner World: An Introduction to the Neuroscience of Subjective Experience*. New York: Other Books, 2003.
- Daniel Tammet. *Born on a Blue Day: A Memoir*. New York: Free Press, 2007.
- Taylor, Jill Bolte. "Stroke of Insight." *TED: Ideas Worth Spreading*. March, 2008. [http://www.ted.com/talks/jill\\_bolte\\_taylor\\_s\\_powerful\\_stroke\\_of\\_insight.html](http://www.ted.com/talks/jill_bolte_taylor_s_powerful_stroke_of_insight.html) (accessed January 26, 2012).
- Wurtzel, Elizabeth. *More, Now, Again: A Memoir of Addiction*. New York: Scribner, 2002.