“Fix my voice,” she says, sounding conspiratorial. “I want to talk to the kids. I want to answer the phone.”

“I know,” I answer glumly as I watch cancer ravage her body. She undergoes chemotherapy despite my not-so-veiled attempts to dissuade her. “My kids must know that I tried.”

Her husband squeezes her thin fingers, mute with grief. She can't talk above a whisper, so she beseeches me with her eyes instead. Large brown orbs, widened with anxiety, fear, and questions—biggest of all, “Why my kids?”

I like her. She's young, like me. She has children, like mine. My heart twists itself in a knot each time we meet. When I think of her at home with her kids, I see myself. I fret over how to save her while I curse the cruelty of her destiny.

She is admitted with pneumonia. Her lungs are drowning. Our eyes complicit, I send her home to her children. Her husband calls me in a panic. She is on the floor and can't get up. Defeated, she is bundled back into the hospital. She dies, without her family.

I call him. “She made sure we had all gone home,” he says somberly. “Maybe she wanted it that way,” I console him. And as I start to say sorry I realize something horrible: I cannot remember her face. I saw her only a few days ago; this isn't possible! I challenge my treacherous memory to conjure her face, but there is nothing. I associate her only with hoary whispers.

I feel betrayed by my mind. Without a face to attach it to, I find it impossible to file away her memory. At night, I try in vain to summon her features. What kind of doctor simply forgets? I have forgotten names and diseases before, but this is a different kind of forgetting, harder to accept. Did I not care about her as much as I thought? The harder I work to grasp her face, the more amorphous she becomes. I'm as fascinated by the process as I am maddened by the enigma.

I finally surrender the fight against my mind. I'm fascinated by the process as I am maddened by the enigma. I run into her husband as he attends to unpaid bills. I selfishly hope that his fond recollections will breathe life into my memory, but it doesn't work. Each time I see him it feels a little more inappropriate to ask the question I'm still carrying: "What did your wife look like?" The longer I leave it, the more wretched I feel. I flick through hundreds of pages of chart notes documenting her inexorable decline, a thorough paper memory, desperately incomplete like my own. I search for the photograph we never thought to take, the one thing that might have helped me put the patient to rest.

Ranjana Srivastava is a medical oncologist in Melbourne, Australia. In 2004-05 she was a Fulbright scholar at the MacLean Center for Clinical Medical Ethics at the University of Chicago. docranjana@gmail.com

I associate her only with hoary whispers.
Artist William Utermohlen was diagnosed with Alzheimer’s disease in 1995 at age 61. He continued making art for seven years after his diagnosis, switching to drawing after painting became too difficult. Mr. Utermohlen stopped drawing in 2002, and he died in 2007.

The image on the cover is one of the last pieces of art Mr. Utermohlen made. In Head I (2000), the “artist has assimilated his drawing method to his destiny: to subsist while disappearing. … The staring eyes are now like empty dark cavities fixed into a head I turned into a skull.”

Mr. Utermohlen’s primary focus during his career was painting portraits and murals, but after his diagnosis he mostly painted and drew self-portraits. These self-portraits are “unique artistic, medical, and psychological documents. They portray a man doomed yet fighting to preserve his identity and his place at the center of the face of impossibly encroaching on his mind and senses. … In most portraits there is an emphasis on the frontal lobe of the skull, where William knows the source of his illness lies. … Continuity, as much as anything, is evident in [his] self-portraits.” The artist continued to think, observe, concentrate, and paint the facts of his existence even as the darkness closed in.1

From a clinical perspective, three members of a neurology department wrote in The Lancet that Mr. Utermohlen’s post-diagnosis self-portraits “reveal a change commensurate and consistent with the deterioration in his cognitive state, particularly with respect to his visuospatial and visuospatial skills,” yet his “creative impetus wasn’t impaired in the same way” the skills required to implement artistic intentions were.2

Pat Utermohlen, the artist’s wife and an art historian, describes her husband’s work differently. “William bravely began to paint himself, desperately trying to understand what was happening to his mind. … In these self-portraits he faces with heart-breaking intensity William’s efforts to explain his altered self, his fears and his sadness. … There is a new freedom of expression, the paint is applied more thickly, art-historically speaking the artist seems less linear and classical, more expressionist, and I see ghosts of his German heritage.”4

Mr. Utermohlen’s work raises profound questions of identity and its expression. His disease clearly deprived him of the ability to paint with precision, a precision Mr. Utermohlen sometimes sought: “His wife and his doctors said he seemed aware at times that technical flaws had crept into his work, but he could not figure out how to correct them.”5 Yet there’s no way to tell which elements of his post-diagnostic pieces are “flaws” dictated by his illness and which are deliberate choices. The neurology experts write as if Mr. Utermohlen was always attempting “accurate” self-portrayal, and progressively falling short. In contrast, his wife writes that he was trying to “explain his altered self.” Perhaps this evocative series expresses progressive alterations in how he saw himself; perhaps even in pieces like Head I he was adapting to limitations in form and finding new ways to successfully convey how he felt. Or perhaps these self-portraits are the visual equivalent of deteriorating speech, expressions radically distorted by the gap between Mr. Utermohlen’s intentions and his ability to communicate them. “It’s impossible to answer these questions with certainty, but the conversation they inspire between medical professionals, humanitarians, scholars, patients, and families is one of Mr. Utermohlen’s enduring legacies.”—KW

1 “Portraits from the Mind: The Works of William Utermohlen—1955 to 2000,” a touring retrospective of the artist’s work before and after his diagnosis with Alzheimer’s disease, was exhibited at the Chicago Cultural Center last summer.

2 ATRUM thanks Patricia Utermohlen and Galerie Beekel-Obilo-Birole for their generous permission to reproduce William Utermohlen’s work.

3 Chicago Exhibit Catalogue, 23.

4 Chicago Exhibit Catalogue, 5, 22, 23.


6 Pat Utermohlen, September 2006.

stories written in the 1920s and 1930s. The hospital was a fearsome place in Lovecraft’s cosmology. Writing just as reports of unprecedented overcrowding emerged from the hospital, Lovecraft combined Danvers’ dual reputations as the realm of the uncanny and as a place where patients were harmed with impunity. In the pages of Lovecraft’s stories, it was possible for a spirit-possessed visitor to shoot a “madman” in his cell, so lax were patient protections in this storehouse for the “poor[,] struggling bod[ies]” of the “violent and pitiable insane."

But it was folklore, more than published fiction like Lovecraft’s, that usually encapsuated eerie iterations of patient abuse and neglect at Danvers State. Local people told and re-told stories in which the supernatural memoralized and redressed the hospital’s alleged infractions against patients. These tales kept pace with developments at the hospital—hydrotherapy in the 1900s and lobotomy in the 1930s, to the renewed claims of patient ‘warehousing’ and neglect that engulfed the hospital in the 1960s and 1970s. When Nobodys Child, the 1987 memoir of former patient Marie Balter, drew national scrutiny to overcrowding, neglect, and abusive treatment at Danvers (called “Sutton State Hospital” or “The Castle” in Balter’s book), local people not only folded the new events into updated ghost stories, but also contextualized them within the longer history preserved in existing haunting legends. As news of fresh scandals broke, locals opined that the latest patient malpractice misgauge the prevalence of patient ill-treatment in what form would you exist, were your brain anywhere but concealed inside your skull? So an easier question: Can you actually imagine the living brain, complete and accessible, at all? Even for a neurosurgeon, this might pose a challenge. How much of a brain can be seen before it’s no longer alive? If you’ve had medical training perhaps you’ve held a human brain in your hand, and can imagine one now by remembering. But a cadaver brain is not a living brain. Perhaps you’ve looked at a CT scan of the head or a brain MRI, but that doesn’t help because I asked you to imagine those brains, not to picture them. When we imagine we often picture a picture, a representation of a representation.

Imagine a row of living human brains. Can you pick out your own brain? Such impossible self-reflexiveness it of course absurd. With what would you be doing the identifying, were your brain the object of observation? In what form would you exist, were your brain anywhere but concealed inside your skull? So an easier question: Can you actually imagine the living brain, complete and accessible, at all? Even for a neurosurgeon, this might pose a challenge. How much of a brain can be seen before it’s no longer alive? If you’ve had medical training perhaps you’ve held a human brain in your hand, and can imagine one now by remembering. But a cadaver brain is not a living brain. Perhaps you’ve looked at a CT scan of the head or a brain MRI, but that doesn’t help because I asked you to imagine those brains, not to picture them. When we imagine we often picture a picture, a representation of a representation.

Computed Axial Tomography: drawing in slices. Technology's images are, of course, of brains at all, but stylized graphics produced by tracking magnetic fields and electrons, not light, and encoded in colors that do not reproduce the grey matter, or the neurons, or sponginess and blood. As you read this, though, there is at least one live brain in the room with you. So instead of picturing brains, instead try to imagine your own brain on the surface nearest to you. On your desk? On the floor at your feet? (Don’t let it get too dirty.) Is it wet? Heavy? What does it smell like? How does its presence alter the room?

It’s odd that a material object so necessarily present at every moment is also so profoundly invisible, intangible, and inaccessible to us. It’s also absolutely necessary, the fundamental blind spot of all embodied beings. Perhaps this is why my thought experiment may seem disturbing, even obscene. We have such strong cultural injunctions against the revelation, and even the representation, of parts of the body that are hidden when the body is whole. There is a boundary to self-reflexiveness: the brain cannot perceive itself, or the mind cannot perceive the brain. We cannot encounter our inner organs directly, unless in the face of life-threatening violation of our bodily integrity. We tell ourselves that science reveals, where art represents (and the humanities study representations). We tend to trust that biomedical technology has found ways to reveal the inside of the body, but unmediated access is limited instead. The internal organs, like fish, cannot survive for long at the surface. We have to imagine our own individual interiors rather than seeing them, and it is hard to imagine them without also imagining the violent, the gruesome, the graphic. And the medical...

When I was ten, I had an appendectomy. Afterwards, the surgeon gave me my sad little appendix to take home in a plastic bottle with a red screw-top lid. I kept it beside my bed and wondered whether the stuff still inside me...
Our fascination with these impossibly accessible bodies makes sense. Medicine teaches us, particularly in today’s bioscientifically inflected, risk-averse popular culture, that to watch over the insides of our bodies is to take good care of ourselves. Or rather that it would be, if it were possible, and because it is not, we are inclined to pass the responsibility on to medicine, and are disappointed when doctors can’t watch our insides either. In these thwarted expectations lie the seeds of clinical illness anxiety.

People who are anxiously vigilant over their bodies, who obsessively read signs and sensations as symptoms of hidden internal changes are usually diagnosed as hypochondriacs. I understand hypochondria as a problem of knowing and representing. Rather than irrational fear and neurotic grasping for attention, perhaps we should think of it as a quite rational unease about the limits of our ability to know our own bodies, with or without the help of science and technology. This is why hypochondriacs haunt medicine. But medicine needs hypochondriacs, for their resistance to reassurance denotes a fantasy that medicine and hypochondria share: the desire for continuous omniscience, for a benevolent panopticon that offers perpetual surveillance of the insides, detecting and arresting ominous changes as early as possible. Visual images are never adequate because they are static. Like the MRI or the CT scan or the lab values, visual images always capture a particular instant in the course of a dynamic organism. The still image kills. To interpret it is always a kind of autopsy, when what the hypochondriac wants (in theory at least) is an autopsopy or auto-endoscopy: the ability to watch inside oneself in order to notice the moment one's death begins to stir. Hypochondriacs do not want anything left to the imagination, for they imagine horrors inside them far worse than the graphic depiction of an exposed brain.

Graphic brain-imaging (continued from previous page)

was as fragile, little bits flaking off and sifting down through the increasingly murky formalin. I started drawing pictures of people whose brains or hearts or skeletons were visible. I realized that I knew what my nose looked like, but I’d never recognize my liver in a line-up. A teacher called my drawings “disturbing.” I think this was meant as a diagnosis. To represent the insides is either to do something medical, or to be sick. Vesalius's famous 16th-century study of anatomy, the *Fabrica*, includes figures drawn as if they were alive, in lovely landscapes, in some cases helpfully holding up flaps of skin and fat so we can see the structures beneath. These are not, I believe, pictures of animated corpses. These bodies are not supposed to be dead at all. They represent anatomy’s ideal: to see what the insides of the living look like. (Similarly, Vesalius dissected live apes and pigs not to learn about apes and pigs but because human vivisection was—and is—prohibited.) Even flayed or pulled apart so far they must be held up with ropes, these people do not resist the opening of their bodies, or appear to feel it as pain. Their suffering seems existential, as if they are exposed not to violence and death but to a knowledge of themselves as vertiginously complex. They are signs, fictions, despite the scrupulously observed accuracy of the drawings of their organs.
That brain you have there with you right now, if you could look at it (even in the mirror), we’d know there was something seriously wrong. The prohibition against seeing internal organs is not that simple, though. It is also existential, spiritual, moral. To see what we have inside, directly, would be to know ourselves as flesh machines, our vulnerable material parts working beautifully together but finally just objects in the world. Self, spirit, soul: from such demystification directly.

Surgery is the closest we come to watching a brain that is accessible only by a strictly, formal form of human vivisection, permissible of course because of its therapeutic purpose and effective analgesia and anesthesia. Yet the brain must be handled carefully indeed, and when it’s probed, the surgeon relies on the patient’s verbal reports more than on visual cues to guide the operation. The Welsh physician-poet Dannie Abse wrote a poem, “In the Theatre,” about brain surgery. The patient is conscious, the surgeon’s “fingers . . . rash as a blind man’s, inside his soft brain.” Suddenly the patient speaks in a different voice, otherworldly and “artic,” as if his body is a ventriloquist’s dummy for some other source of speech, a voice that keeps repeating, as the patient dies, “leave my soul alone . . .”

Surgery opens us up but we ourselves are kept from watching. Even for the physician, drapes help to bracket a surgical site off from the rest of the living patient. Breaches of such protocols are shocking. A friend who saw her own C-section reflected on the surface of a light above her told me she will never forget watching as her uterus was set aside, her head, on the operating table.

The meaning of the word “graphic” has come to signify not just representation, but specifically the depiction of what is supposed to be hidden. “Graphic sex and violence” describes actions involving the body, especially parts of the body not routinely available to view, exposed (and then represented) only because of sexual activity or violent damage. Such exposure is also facilitated by medical examination and intervention. The 1930 Motion Picture Production Code was the set of restrictions which (until the MPAA began in 1960s) controlled what could and could not be shown in American movies, as well as sex and violence, the list of banned “repellent subjects” included “surgical operations.” Details of surgery were described as “objectionable and offensive” and classed along with “brutality and possible gruesomeness.”

The concept of nudity goes beyond the surface; body parts usually hidden either by clothes or by skin were taboo. This has changed. Televised surgery—real surgery (though edited) on real bodies, not just special effects—is accepted largely because it claims to be educational rather than entertaining. And fiction film seems to have no limits at all. In Hannibal, a sequel to the serial killer thriller Silence of the Lambs, Hannibal Lecter drugs a US Justice Department agent named Paul Krendler, seats him at the dinner table, and performs a craniotomy on him. When his colleague Clarice Starling joins them for dinner, Lecter removes not only Krendler’s baseball cap but also the top of his skull. In a parody of neurosurgery Krendler converses, slurring somewhat, with Starling, while she and we know there was something seriously wrong. The prohibition against seeing internal organs is not that simple, though. It is also existential, spiritual, moral. To see what we have inside, directly, would be to know ourselves as flesh machines, our vulnerable material parts working beautifully together but finally just objects in the world. Self, spirit, soul: from such demystification directly.

The image on the cover of this issue of ATRIUM is one of William Utermohlen’s last self-portraits. The drawing records the progression of his Alzheimer’s disease as it nears complete destruction of his ability to draw. But until that point, Utermohlen kept re-drawing himself, even as he, at the alterations in his brain changed how he drew himself, and even (as far as we can tell) how he saw and imagined himself. His self-portraits mediate and represent what medicine could not apprehend directly. They are a symptomatic record of the disorganization of his living brain, the organ itself out of reach until after his death, when it could finally be handled and examined by others. An earlier work is titled Self Portrait (WeiSa).
My Shadow Uncle

Kristi L. Kirschner, MD

"Why did you become a rehab doc?" I've fielded with incomplete answers to this question for years: "I'm interested in holistic medicine," "I value longitudinal relationships," "Human and civil rights issues have always interested me," etcetera. Though these are all true, I always knew there was a missing link. Recently, I've realized what that link is, and why it's been missing—because it's my "shadow uncle," Uncle Bobby.

I call my Uncle Bobby a "shadow" because until I began researching his life, I knew of him only in the sketchiest of terms. He was my father's youngest sibling, born in 1929 in the midst of the Great Depression. When Bobby was just a year old, his 34-year-old mother Lillian died of rheumatic heart disease. When Lillian was found dead, my father and his sisters took turns staying by in the small farmhouse. Bobby—still too young to be a nurse—had to be taken off her breast.

That changed in 1939. At the age of seven, Bobby was placed in an institution in Marshall, Missouri. Bobby's disability, but the harshness of the times, was still caught up in the allure of eugenics, even sporting "fittest family" contests at State Fairs. I now wonder if the narrative of disability-as-tragedy was still caught up in the allure of eugenics, even sporting "fittest family" contests at State Fairs. I now wonder what if his family had been supported in providing care for him in the community? What if his siblings' needs weren't pitted against Bobby's needs for care?

Questions like these flow freely through my mind as I ponder the pressing needs of my patients and their families. Disabilities and human differences don't have to result in tragedy. I can't rewrite the ending of Bobby's life story, but I can round out the picture, fill in the details, and embrace him as a valued uncle I wish I could've known. In addition, by re- cog nizing the psychological "shadow" role he played in my family, I find that a much richer, integrated, and complex story of humanity emerges. And for now, that's the best answer I have for why I'm a rehab doc.

As Bobby's shadow was illuminated, I realized the tragedy wasn't so much Bobby's disability, but the harshness of the times and the social response to a child and family in need. Through no fault of his own, my uncle was disabled. Through no fault of their own, their families. Disabilities and human conditions aren't pitted against Bobby's needs for care in the community? What if his siblings' needs weren't pitted against Bobby's needs for care?

Questions like these flow freely through my mind as I ponder the pressing needs of my patients and their families. Disabilities and human differences don't have to result in tragedy. I can't rewrite the ending of our lives that can impel us in powerful ways. Often these shadows are painful episodes or thoughts we believe we can't endure, so we dissociate from them or submerge them. Invariably, though, they reappear in the sub terrain of our minds, unconsciously affecting our decisions and behaviors. I believe that's what happened to my father. The tragedy of losing his mother, the complex feelings he had about his brother, and the horrific images of institutionalized disabled children created reactionarily, and largely unconscous, fears that permeated my family's life. In turn, I absorbed these lessons about disability, both spoken and those left unsaid. When I was twelve, my 37-year-old mother was unexpectedly pregnant—much to my delight and much to my father's despair. He was terrified she would have a child with a disability. They had "rolled the dice three times and been lucky—why press it?" The tension in the house throughout the pregnancy made me miserable and defied my understanding. I recall the palpable collective sigh of relief when she delivered a beautiful baby boy with ten fingers and ten toes.

My Uncle Bobby wasn't just a fuzzy figure in my mind; I believe he was a psychological "shadow" in my family's life, and by extension mine as well. Marshall was a good distance from Lake
Illness Narratives in Art

Paul M. Wangenheim, MD

Illness narratives are created when patients tell their stories to the world, and the private experience of suffering is brought out in the open. Only patients can tell their true stories before they are taken over and transformed into medical histories. Narrative competence is the ability to understand and retell these stories and it can bridge the gap between the sick and those who care for them.1

Literature provides us with the largest source of narrative material, but narratives aren’t limited to the written word. They can also be found in the close reading of paintings. Painters have used their artwork to tell stories from as long ago as cave paintings, hieroglyphs, and Grecian urns. Writers use plot, context, voice, and metaphor to weave stories. Artists use line, color, forms, and allegory to create the narratives we see on the canvas. Each one has a story to tell for those who are willing and able to listen. There are parallels in the connection that is forged between reader and writer, and viewer and painter, and narrative competence can be acquired from both sources.

Many illness narratives in art are found in the genre of portraiture. Narratives are portrayed in realistic, figurative pieces. The portrait artist sets context by choosing a locale. Plot is represented by the arrangement and interaction of the figures in the painting. The inclusion of objects in the painting adds elements of detail to the story. Voice is established by gestures and facial expressions, and on occasion, by looking the viewer directly in the eye. Allegorical symbols in paintings can replicate the power of the written metaphor.

Although there are similarities between the lessons learned from writers and painters, art is not processed and understood in the same way as prose. Reaction to art is driven by a visual and often instantaneous impression; it is a personal experience and highly interpretive. The artist’s creativity and the viewer’s interpretive combination to create meaning. A painting is limited to one moment of time, captured in a single scene. The painter must work with these temporal limits, but at the same time, she or he is armed with the power of visual representation to create words in the viewer’s mind. Paintings must be read again and again. As with prose, close reading reveals the work’s subtle meanings and messages.

Medical narratives are found in portraits of the sick, in scenes of suffering, and in depictions of the relationship between doctor and patient. The most powerful narrative, the first-person illness narrative, is produced when artists themselves suffer and create self-portraits. An example of this kind of first-person narrative can be found in the works of Francisco Goya y Lucientes, one of Spain’s greatest artists. He was at the pinnacle of his career when illness struck. Goya was flourishing as the beneficiary of royal patronage. He painted the wealthy, the famous, and the carefree, idyllic lives they lived. In 1792, while commissioned to paint a series of scenic tapestries depicting aristocratic Spanish life, he fell ill. He suffered high fevers, followed by paralysis, partial blindness, severe vertigo, and roaring tinnitus. He barely survived and was left permanently deaf.2 At only forty-six, Goya was visited by the specter of death. It would haunt him for the rest of his life.

Goya’s illness found a voice in his art: a narrative of his affliction, his fear of death, his realization of the dark side of life, and the story of his suffering. In the years following his illness, Goya produced a series of numbered prints entitled Los Caprichos (“Whims”). They marked his departure from colorful, stylized portraits to portrayals of the dark and macabre side of life. In No. 43, El sueño de la razón produce monstruos (“The sleep of reason produces monsters”), 1796-1797, we see a man draped over his desk, sleeping in an uncomfortable position. A flock of malevolent owls and bats with their wings ominously spread circle over his head, haunting his dreams. A lynx, the symbol of the afterlife, watches the macabre scene.

Los Caprichos also reflects Goya’s tormented soul. No. 40, ¿De que mal morirá? (“Of what illness will he die?”), 1796-1797, portrays a doctor—patient relationship. (Fig.1) A moribund patient lies on a bed. A witless physician, portrayed as a donkey resplendent in a suit, examines the pulse. In the background hooded figures wait, just beyond the bedside scene. Death looms while the patient lies helplessly between the incompetent physician and the fearsome unknown.

Goya survived his illness, and he lived with and painted his dark visions for nearly forty more years, including a period of troubling works referred to as the “Black Paintings.” At the age of eighty-two, after a relapse, he painted another doctor-patient portrait with an entirely different story. In Goya cura a por el doctor Arrietta, (familiarly known as “Self-portrait with Dr. Arrieta”), 1820, the artist speaks to us in the first person. (Fig.2) He looks directly at the viewer. His body is the narrative. His age, weakness, and hemiparesis are all evident. His doctor is beside him offering him an allegorical cup of human kindness; his strong horizontal arm braces the patient. The shadowy figures are ever present, but this time the physician stands between the patient and his fears. Goya included a handwritten testimony of gratitude before the work in the style of a religious votive, crediting his doctor with curing him. The painting is reminiscent of Arthur Frank’s “communicative body,” with Goya’s own body telling the story. As Frank explains, “Human communication with the world, and the communication this communication rests on, begins in the body.”

Illness forever changed the nature of Goya’s paintings. Reading Goya’s paintings, we learn the story of a devastating illness, the resulting fear of death, and the physical ravages of a chronic illness. The initial narrative of anger and fear is replaced with one of resignation and gratitude. As Arthur Kleinman writes: “The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering.”

Illness narratives can be found in paintings as well as text. Goya tells us his story with powerful images. He was haunted by his brush with death, and his art reflected the profound change illness had on his life. Art is an immense resource of narrative material, and narrative competence can be gained by close reading of the powerful stories paintings can tell.

Paul Wangenheim is in the private practice of cardiology. He is also a faculty member in medical humanities at St. Barnabas Medical Center, Livingston, NJ, and is a doctoral candidate in Medical Humanities at Drew University, Madison, NJ. paulw@3300and.com

Fig. 1

Fig. 2

Sleeping with ghosts: Cognition, emotion, and scholarship

Debajani Mukherjee, PhD

I’m lying in a bunk bed in a building where Nazis murdered people with disabilities, and the shadows are ominous. What was that noise? Who was tortured here? And what am I learning by sleeping in a former killing center in Hesse, Germany? I toss and turn, trapped in an academic nightmare.

This isn’t what I bargained for when I joined a summer institute on “Disability Studies and the Legacies of Eugenics in Germany.” I expected my brain would be crammed full of new facts about state-sponsored torture and extermination, disability-stigma, bureaucracy, pseudoscience, and propaganda. I didn’t expect the details would swirl around my head while I lie on this bunk in the darkness, or that my heart would be full of unbearable sadness, overwhelming heaviness, and despair. I shut my eyes hard and plug my ears—maybe ghosts can’t scare you if you can’t see or hear them. Still, I swear I can feel them. I experienced a dichotomy between what I knew and what I felt on this research trip, but a growing body of research questions this split between the rational and the emotional, or as psychologists parse it, cognition and emotion. The neurologist Antonio Damasio, in his classic emotion. The neurologist Antonio Damasio, in his classic 

antichristian nightmare.

When I sit down to write a lecture or an academic piece on what I learned in Germany, all those feelings come back to me. The way I process and remember the information is linked to the experience itself. As psychotherapy expert Leslie Greenberg notes, “Memories are thus marked to set off emotional responses that were set off by the original event. The next time something is recalled, the person will feel the same way unless the emotion-schematic memory and associations linked to it are revised.” It’s hard for me to disentangle the disturbing facts and thoughts from the visceral chill and sadness. Sitting at my desk in Chicago, I feel the disabled ghosts at the Hadamar Memorial in Hesse; my chest tightens the way it did when I could barely breathe in the basement of a psychiatric institution. I feel sorrow, anger, and despair. Does the inseparability of my cognition and my emotion on this research trip mean I can’t take a scholarly approach to the topic? Or is it false to assume that scholarly work isn’t informed and shaped by emotion, in the seamless (and sometimes less-than-seamless) way our brains process complex information? This experience also sensitized me to the contrast between studying killing centers through text and classroom work, and the experience of visiting the killing centers. As I read articles to prepare for the summer institute I could choose to put them down; I could control the amount of time that I immersed myself in the topic. When I discussed it in classroom-style settings I found the topic depressing, but in an abstract way. During our summer institute in Pondam, I read and discussed the following passage from an academic text:

In the Fall of 1940, Kaufmann visited Bernberg, confiscated a portion of the institution for T4 (“T”) refers to Tiergartenstrasse Number 4, the address where the plans for this phase of euthanasia were created, supervised remodeling, and arranged the transfer of staff from Brandenburg, . . . [U]like most other killing centers, the old Bernberg (psychiatric) institution continued its operations, sharing property and buildings with the killing center.”

When we visited the Bernberg Memorial I’d read about, part of a still-functioning psychiatric institution which has been continuously operating since the early 1900s, I could feel the disabled ghosts. I imagined them watching us go down to the gas chambers in the basement, down wheelchair-inaccessible stairs, where some of my colleagues with physical disabilities had to literally be carried down the stairs by hospital staff wearing white coats! I went to Germany knowing key facts and analyses, but I was completely unprepared for the physical, emotional, and cognitive experience of visiting institutions where disabled people were killed en masse. The experience of the site-visits was intensified by our group process. We all chose to spend a summer month delving into legacies of euthanasia; we had written about and studied injustice and discrimination. We shared a basic understanding of disability as a social category, and together we rediscovered and claimed the history. Day after day we researched the topic with a persistence that is typically desirable in an academic endeavor. However, this collegiality had its emotional toll as well. Alone, I wouldn’t have spent free-time watching Nazi propaganda or listening to true-life disability horror stories, linking them to current-day practices and perseverating on how crappy and unfair the world can be. At Bernberg the emotional expressions of my new colleagues—blank stares, welling tears, fearful faces—added to my own horror. The sight of people in white coats carrying group members down the stairs to the site of the gas chambers and the fact that the institution still operated as a mental hospital reinforced the medical model of disability. As a non-disabled psychologist who works at a rehabilitation hospital, I felt implicated by association.

I was ready to leave the Bernberg Memorial after about two hours, but we stayed for a full day of data gathering and inquiry. From my perspective, we were on an unrelenting search for data in the face of the horror (and for some, the terror) we were feeling. After the tour of the gas chambers, around hour five, I had to leave the building and get some air. I sat on a bench and wrote in my journal. I didn’t want to learn about what I’d seen; I didn’t want to hear more; I definitely didn’t want to listen, analyze, or discuss the topic as a scholarly pursuit. I needed to be alone and process, to find some reprieve. When I rejoined the group, we learned more disturbing facts and lingered in the rooms adjacent to the gas chambers. Later we returned to the basement and spontaneously had a memorial service for the victims. Some sang, others danced, I chanted a Hindu prayer. Using a different part of my brain, I conjured positive energies and tried to find comfort in sharing the sorrow. For a few brief moments, it felt okay.

Obviously this particular summer institute is an extreme example, but we often underestimate the emotional nature and content of academic work in the medical humanities and bioethics in general. We’ve learned from people with brain damage that an inability to process emotional information affects decision-making, social judgment, and interpersonal relationships. Yet a part of me would rather avoid these memories and I’m not sure I have fully processed the emotional information—four years after the fact the memories are still raw and my brain jumps to the painful feelings. So I work to turn off some of that emotion when I have to lecture or write on the topic, or even on issues closely related to it. Academics are quick to push emotion aside and go for the cognitive analysis, but all of our work is driven to some extent by what we’re feeling, especially in ethics, where ideas of right and wrong can be deeply held and visceral. I wish I didn’t continue to feel haunted by this project, yet it taught me valuable lessons about the false dichotomy between cognition and emotion, and the role of both in the practice of medical humanities and bioethics. And those lessons are welcome to linger.

Debajani Mukherjee is a clinical psychologist. Associate Director of the Rehabilitation Institute of Chicago Donnelley Family Disability Ethics Program, and Assistant Professor of Physical Medicine and Rehabilitation and Medical Humanities and Bioethics, Feinberg School of Medicine, Northwestern University. dmukherje@riso.org

observation that patient maltreatment has traditionally been “invisible” and “subject to denial” within the hospital setting. As Judith Richardson explains, haunting has great value as an egitariatric historical record. Ghosts, she writes, “are produced by the cultural and social life of the communities in which they operate as a particular, and peculiar, kind of social memory, an alternate form of history-making in which things usually forgotten, discarded, or repressed become foregrounded ... as items of fear, regret, explanation, or desire.” For Richardson, hauntings represent the means by which contemporary people recall and reckon with persons or events once rendered “marginal and invisible.” Thus, through haunted hospital myths that focus upon ethical transgressions against patients, the public has not only memorialized those patient populations whom historical instances of purported abuse, neglect, and maltreatment once marginalized, but has also given those patients voice, agency, and, by extension, a measure of justice. For these reasons, medical ethicists and medical historians would do well to examine the haunted hospital folklore that has once marginalized, but has also given those patients voice, medicare, and public memory. (continued from page 2)

Haunted hospital stories at the heart of these depictions often encapsulate not only genuine history, but also a record of public referenda on various aspects of 19th- and 20th-century hospitals—from their architecture and appearance, to the new technologies and treatments employed within them.

For recent presentations of haunted hospital legends in popular culture, see: “Trans-Allegheny Lunatic Asylum, Weston, West Virginia,” Ghost Hunters, Sci-Fi Channel, April 30, 2008; Haunted Asylum (Diament State Hospital), VH1, directed by Maryanne Patterson (Pittsburgh, PA); PPS Productions, 2002; and Mark Mariniak, “When Darkness Falls at Central State (Haunted Indiana Part 3 Book Excerpt),” Ghost of the Prairie Without, prairieghosts.com/central_state.html (accessed August 30, 2008).

4 DeLancey, “Eishes, Cultural Memory, and Public Perceptions of Medicine.”
5 Ibid.

3 For recent presentations of haunted hospital legends in popular culture, see: “Trans-Allegheny Lunatic Asylum, Weston, West Virginia,” Ghost Hunters, Sci-Fi Channel, April 30, 2008; Haunted Asylum (Diament State Hospital), VH1, directed by Maryanne Patterson (Pittsburgh, PA); PPS Productions, 2002; and Mark Mariniak, “When Darkness Falls at Central State (Haunted Indiana Part 3 Book Excerpt),” Ghost of the Prairie Without, prairieghosts.com/central_state.html (accessed August 30, 2008).

4 DeLancey, “Eishes, Cultural Memory, and Public Perceptions of Medicine.”
5 Ibid.

3 For recent presentations of haunted hospital legends in popular culture, see: “Trans-Allegheny Lunatic Asylum, Weston, West Virginia,” Ghost Hunters, Sci-Fi Channel, April 30, 2008; Haunted Asylum (Diament State Hospital), VH1, directed by Maryanne Patterson (Pittsburgh, PA); PPS Productions, 2002; and Mark Mariniak, “When Darkness Falls at Central State (Haunted Indiana Part 3 Book Excerpt),” Ghost of the Prairie Without, prairieghosts.com/central_state.html (accessed August 30, 2008).

4 DeLancey, “Eishes, Cultural Memory, and Public Perceptions of Medicine.”
5 Ibid.

3 For recent presentations of haunted hospital legends in popular culture, see: “Trans-Allegheny Lunatic Asylum, Weston, West Virginia,” Ghost Hunters, Sci-Fi Channel, April 30, 2008; Haunted Asylum (Diament State Hospital), VH1, directed by Maryanne Patterson (Pittsburgh, PA); PPS Productions, 2002; and Mark Mariniak, “When Darkness Falls at Central State (Haunted Indiana Part 3 Book Excerpt),” Ghost of the Prairie Without, prairieghosts.com/central_state.html (accessed August 30, 2008).

4 DeLancey, “Eishes, Cultural Memory, and Public Perceptions of Medicine.”
5 Ibid.

3 For recent presentations of haunted hospital legends in popular culture, see: “Trans-Allegheny Lunatic Asylum, Weston, West Virginia,” Ghost Hunters, Sci-Fi Channel, April 30, 2008; Haunted Asylum (Diament State Hospital), VH1, directed by Maryanne Patterson (Pittsburgh, PA); PPS Productions, 2002; and Mark Mariniak, “When Darkness Falls at Central State (Haunted Indiana Part 3 Book Excerpt),” Ghost of the Prairie Without, prairieghosts.com/central_state.html (accessed August 30, 2008).

4 DeLancey, “Eishes, Cultural Memory, and Public Perceptions of Medicine.”
5 Ibid.

3 For recent presentations of haunted hospital legends in popular culture, see: “Trans-Allegheny Lunatic Asylum, Weston, West Virginia,” Ghost Hunters, Sci-Fi Channel, April 30, 2008; Haunted Asylum (Diament State Hospital), VH1, directed by Maryanne Patterson (Pittsburgh, PA); PPS Productions, 2002; and Mark Mariniak, “When Darkness Falls at Central State (Haunted Indiana Part 3 Book Excerpt),” Ghost of the Prairie Without, prairieghosts.com/central_state.html (accessed August 30, 2008).

4 DeLancey, “Eishes, Cultural Memory, and Public Perceptions of Medicine.”
5 Ibid.

3 For recent presentations of haunted hospital legends in popular culture, see: “Trans-Allegheny Lunatic Asylum, Weston, West Virginia,” Ghost Hunters, Sci-Fi Channel, April 30, 2008; Haunted Asylum (Diament State Hospital), VH1, directed by Maryanne Patterson (Pittsburgh, PA); PPS Productions, 2002; and Mark Mariniak, “When Darkness Falls at Central State (Haunted Indiana Part 3 Book Excerpt),” Ghost of the Prairie Without, prairieghosts.com/central_state.html (accessed August 30, 2008).

4 DeLancey, “Eishes, Cultural Memory, and Public Perceptions of Medicine.”
5 Ibid.
likelihood of death. This time, I wasn’t. The patient—the person—whose obituary I read in the airport was someone I’d gotten to know over several months, including an unexpectedly long hospitalization, followed by several shorter stays. I don’t remember why I thought she was a scholar. Perhaps it came up during a chat, perhaps she was, to me, a familiar type with familiar accessories: newspapers, books, laptop. She was chic; she always wore her own pajamas, favoring bold stripes and prints. She had lots of visitors, and she introduced me to them by name—me, a mere volunteer! Perhaps she had the academic’s knack of having to learn new names every semester; perhaps she was a gracious hostess at all times. During that first long stay, we mostly talked about current affairs. She was smart, sharp-witted, confident. Eventually she had lots of visitors, and she introduced me to them by name—me, a mere volunteer! Perhaps she had the academic’s knack of having to learn new names every semester; perhaps she was a gracious hostess at all times. During that first long stay, we mostly talked about current affairs. She was smart, sharp-witted, confident. Eventually she was discharged—back into the game, I imagined.

She was smart, sharp-witted, confident. Eventually she was discharged—back into the game, I imagined. And that was that, until I read her obituary, a few months later. She had died. She was in bed, bald now from chemo. A friend had seen her name on the patient census, and stopped in to visit. She was discharged—back into the game, I imagined. And that was that, until I read her obituary, a few months later. She had died. She was in bed, bald now from chemo. A friend had seen her name on the patient census, and stopped in to visit.

But raising the question of what is haunting about Freud seems to lead to a re-tread of old debates about Freud’s personality. A more interesting question is how the concept of haunting itself functions in Freud’s writing. This inquiry leads to an important distinction Freud made between the word “haunt” and the related notion of “the uncanny,” a difference which holds significant implications for thinking about the psychoanalytic approach as well as current models of psychiatry.

In 1919 Freud wrote what is considered today one of the century’s most influential pieces of literary theory: Titled “The Uncanny,” the essay investigates the peculiar affect that arises when something that was once familiar, cozy, and “homely” becomes strange and frightening—a doll or mannequin becomes animate; a person glimpses their own double; someone fleetingly wishes death upon another and it quickly comes to pass. Freud distinguishes the uncanny from the usual understanding of “haunted” which, he writes, is both a common mistranslation of uncanny (unheimlich in German) and too bound up—for his purposes—with images of the ghoulish, the spooky, and the strange. However, it is not completely clear why Freud finds it necessary to study the uncanny in the first place, and why this infrequent phenomenon makes him (temporarily) set aside his clinical investigations for aesthetic ones. He does make some suggestive comments in the essay’s opening pages, where he states that the uncanny has its own “specific affective nucleus” which should allow him to locate it “within the field of the frightening.” But this still leaves open the question as to why this “nucleus” needs to be distinguished in the first place.

Even though Freud doesn’t say so explicitly, his conception of the uncanny is more than a tool of literary analysis. It can also be seen as central to an understanding of some foundational psychoanalytic ideas. Further, Freud’s juxtaposition of the uncanny and the haunted could help to illuminate two competing contemporary psychiatric approaches to a condition which abounds in his work more than any other: obsessive neurosis, or as it is known today, obsessive compulsive disorder (OCD). As noted above, Freud’s aim in the essay is to show that far from being induced merely by new, strange, and unfamiliar elements, the uncanny is aroused by those things that are or have been familiar to us. There are essentially two ways in which this occurs. First, when an incident occurs which, to us, is familiar today, obsessive compulsive disorder (OCD).

The Penguin Freud Reader, a central volume in Penguin’s new series of translations of Sigmund Freud’s writing, abounds with references to the spectral nature of the famous doctor and his work. In the introduction, general editor Adam Phillips states that he has assembled the various pieces in order to allow “the curious, who are by definition not the converted, to discover what, if anything, is haunting about Freud’s writing.” That “haunting” concept is reinforced by the paperback’s front cover, where a large white photograph of half of Freud’s disembodied head sits against a black backdrop. On the back cover, a smaller image of Freud’s head floats under a publisher’s blurb describing Freud as “one of the most haunting writers of the modern age.”

In 1919 Freud wrote what is considered today one of the century’s most influential pieces of literary theory. Titled “The Uncanny,” the essay investigates the peculiar affect that arises when something that was once familiar, cozy, and “homely” becomes strange and frightening—a doll or mannequin becomes animate; a person glimpses their own double; someone fleetingly wishes death upon another and it quickly comes to pass. Freud distinguishes the uncanny from the usual understanding of “haunted” which, he writes, is both a common mistranslation of uncanny (unheimlich in German) and too bound up—for his purposes—with images of the ghoulish, the spooky, and the strange. However, it is not completely clear why Freud finds it necessary to study the uncanny in the first place, and why this infrequent phenomenon makes him (temporarily) set aside his clinical investigations for aesthetic ones. He does make some suggestive comments in the essay’s opening pages, where he states that the uncanny has its own “specific affective nucleus” which should allow him to locate it “within the field of the frightening.” But this still leaves open the question as to why this “nucleus” needs to be distinguished in the first place.

Even though Freud doesn’t say so explicitly, his conception of the uncanny is more than a tool of literary analysis. It can also be seen as central to an understanding of some foundational psychoanalytic ideas. Further, Freud’s juxtaposition of the uncanny and the haunted could help to illuminate two competing contemporary psychiatric approaches to a condition which abounds in his work more than any other: obsessive neurosis, or as it is known today, obsessive compulsive disorder (OCD).

As noted above, Freud’s aim in the essay is to show that far from being induced merely by new, strange, and unfamiliar elements, the uncanny is aroused by those things that are or have been familiar to us. There are essentially two ways in which this occurs. First, when an incident occurs which, to us, is familiar today, obsessive compulsive disorder (OCD).

The Penguin Freud Reader, a central volume in Penguin’s new series of translations of Sigmund Freud’s writing, abounds with references to the spectral nature of the famous doctor and his work. In the introduction, general editor Adam Phillips states that he has assembled the various pieces in order to allow “the curious, who are by definition not the converted, to discover what, if anything, is haunting about Freud’s writing.” That “haunting” concept is reinforced by the paperback’s front cover, where a large white photograph of half of Freud’s disembodied head sits against a black backdrop. On the back cover, a smaller image of Freud’s head floats under a publisher’s blurb describing Freud as “one of the most haunting writers of the modern age.”

In 1919 Freud wrote what is considered today one of the century’s most influential pieces of literary theory. Titled “The Uncanny,” the essay investigates the peculiar affect that arises when something that was once familiar, cozy, and “homely” becomes strange and frightening—a doll or mannequin becomes animate; a person glimpses their own double; someone fleetingly wishes death upon another and it quickly comes to pass. Freud distinguishes the uncanny from the usual understanding of “haunted” which, he writes, is both a common mistranslation of uncanny (unheimlich in German) and too bound up—for his purposes—with images of the ghoulish, the spooky, and the strange. However, it is not completely clear why Freud finds it necessary to study the uncanny in the first place, and why this infrequent phenomenon makes him (temporarily) set aside his clinical investigations for aesthetic ones. He does make some suggestive comments in the essay’s opening pages, where he states that the uncanny has its own “specific affective nucleus” which should allow him to locate it “within the field of the frightening.” But this still leaves open the question as to why this “nucleus” needs to be distinguished in the first place.

Even though Freud doesn’t say so explicitly, his conception of the uncanny is more than a tool of literary analysis. It can also be seen as central to an understanding of some foundational psychoanalytic ideas. Further, Freud’s juxtaposition of the uncanny and the haunted could help to illuminate two competing contemporary psychiatric approaches to a condition which abounds in his work more than any other: obsessive neurosis, or as it is known today, obsessive compulsive disorder (OCD).

As noted above, Freud’s aim in the essay is to show that far from being induced merely by new, strange, and unfamiliar elements, the uncanny is aroused by those things that are or have been familiar to us. There are essentially two ways in which this occurs. First, when an incident occurs which, to us, is familiar today, obsessive compulsive disorder (OCD).

The Penguin Freud Reader, a central volume in Penguin’s new series of translations of Sigmund Freud’s writing, abounds with references to the spectral nature of the famous doctor and his work. In the introduction, general editor Adam Phillips states that he has assembled the various pieces in order to allow “the curious, who are by definition not the converted, to discover what, if anything, is haunting about Freud’s writing.” That “haunting” concept is reinforced by the paperback’s front cover, where a large white photograph of half of Freud’s disembodied head sits against a black backdrop. On the back cover, a smaller image of Freud’s head floats under a publisher’s blurb describing Freud as “one of the most haunting writers of the modern age.”

In 1919 Freud wrote what is considered today one of the century’s most influential pieces of literary theory. Titled “The Uncanny,” the essay investigates the peculiar affect that arises when something that was once familiar, cozy, and “homely” becomes strange and frightening—a doll or mannequin becomes animate; a person glimpses their own double; someone fleetingly wishes death upon another and it quickly comes to pass. Freud distinguishes the uncanny from the usual understanding of “haunted” which, he writes, is both a common mistranslation of uncanny (unheimlich in German) and too bound up—for his purposes—with images of the ghoulish, the spooky, and the strange. However, it is not completely clear why Freud finds it necessary to study the uncanny in the first place, and why this infrequent phenomenon makes him (temporarily) set aside his clinical investigations for aesthetic ones. He does make some suggestive comments in the essay’s opening pages, where he states that the uncanny has its own “specific affective nucleus” which should allow him to locate it “within the field of the frightening.” But this still leaves open the question as to why this “nucleus” needs to be distinguished in the first place.

Even though Freud doesn’t say so explicitly, his conception of the uncanny is more than a tool of literary analysis. It can also be seen as central to an understanding of some foundational psychoanalytic ideas. Further, Freud’s juxtaposition of the uncanny and the haunted could help to illuminate two competing contemporary psychiatric approaches to a condition which abounds in his work more than any other: obsessive neurosis, or as it is known today, obsessive compulsive disorder (OCD).
long familiar to the psyche and was estranged from it only through being repressed." This is the exact approach of psychoanalysis, which, as Freud repeatedly points out in his clinical works, is to make the neurotic patient conscious that their present actions are not "normal" but are in fact an "acting out" of childhood experiences. As he states in his later work: "The analyst's task is always to turn the patient away from the threatening illusion; to show him again and again that what he takes to be a new, real life actually is a reflection of the past." The analyst does this by drawing out these repressed memories of the past, in order to make him or her "do battle" and essentially work through these symptoms. This is made possible because symptoms are no longer seen as strange and intrusive, but once-familiar and therefore part of one's own history. They are no longer to be excised, but tangled with; psychoanalysis then, helps the patient view symptoms as uncanny rather than haunting.

But as this "psychodynamic model" has largely been supplanted by the "medical model" of mental illness in the last 25 years, a "haunting" view of symptoms has become predominant. Haunting in this sense is different from the uncanny in that it does not include the "familiar" (heimlich) element which is so central for Freud. This means that neurotic symptoms are not seen as part of a coherent past, but rather as intrusive, alien, and in need of excision. Recent behavioral approaches can contribute. Instead of this approach can be that the patient see their obsessional symptoms not as foreign and strange (although perhaps frightening), but as part of a coherent self; uncanny rather than haunting, and therefore easier to confront.

Jon Mavin-Peters is a Research Assistant at Feinberg School of Medicine, Northwestern University. In the fall of 2009 he will begin graduate school in political theory. pmavinpeters@northwestern.edu

6 Anthropologist Tanya Luhrmann recently noted the case of a schizophrenic patient who is "adamantly opposed to the medical model because to him it makes his thoughts, his goals, and his desires seem as if they are not really his own but due to something separate from himself." Quoted in Fleissner, p. 128.
I didn’t want to be part of his household, but I was drawn into the circle just by doing my job.

Louie never left John, kept out of the sterile area only by an equally tough operating room supervisor. She too had her hard rules, her closed family of operating room personnel. I was a surgeon. John improved quickly; the damage to his heart appeared to be minimized. He raised the blood pressure and decreasing the work of the heart.

Everything falls on him. These deaths suggest failure of not just of intellect but also of hand, bad technique. But I had miscalculated. My comfort faded. No easy way out. Within twenty-four hours John slipped back into shock, forcing us to insert a balloon into the other leg, after which he was transported directly to the cardiac catheterization laboratory, where angiography revealed severe blocks and a heart muscle that contracted feebly, a dying bird. The odds were terrible for John. Few survive open-heart surgery in cardiogenic shock.

“What are his chances?” Louie asked. I moved away quickly, barely nodding. “We’ll see.”

Not an easy decision—the consequences of failure loomed. Suppose. Suppose. Suppose. The surgeon and John died! Would the family spoil their anger over me? Would Louie seek revenge? Or could I decide not to operate and walk away without criticism, an uncomplicated and effortless exit. Without surgery John would surely die, and a new leader would emerge. Perhaps the new boss would find another surgeon. The pressure to perform would be off. But training won. Cardiac surgeons are in the rescue business. Any chance of saving a life, no matter how slim, we try. I rode the elevator to the operating room and got my gear. The heart-assist device was connected to an external pump that filled and collapsed the “balloon” in response to the heart cycle, raising the blood pressure and decreasing the work of the heart.

I came to the side of his bed. The bed rails were down. John lay under the sheets, silent. For a few seconds I wondered if a stroke had left John speechless. Then his arms, big and still muscular, reached out, captured my head, twisted down, and curled my ear to his mouth.

I imagined the headline: Deranged Patient Kills Surgeon By Strangulation. Then like an avalanche, the words, mouth to ear, slid naturally, unashamed and continuous, a whisper. “If you want someone killed, I’ll do it and no one will ever know.” Louie, for the first time since I’d known him, smiled widely. He understood. He knew the words without hearing. John waited silently for a name.

“Why open your heart? Why open his?”

To openly refuse John’s offer would be to slit him, something I never wanted to do. So I remained thoughtful. An anesthesiologist who blocked the development of cardiac surgery. A contractor whose roof repair leaked. My second inclination was to ask for a rain check. Who knows? My third and last inclination, the only correct one, was prostrated silence. How could I explain the irony, a life for a life. John, I deemed, took the death of my larynx as an indication that I accepted his offer as it was intended, a supreme symbol of his gratitude. One I could take advantage of whenever I was in need.

I don’t believe one should take offense at John’s method of bartering. After all, the ways patients thank their doctors vary. Some folks have good insurance; some families bring Chinese or pickles to the office. Some cry when they thank you or kiss your hands. It may come down to what’s most easily available.

I saw John frequently after he left the hospital. Always with Louie, who now smiled at me as if I were his favorite grandson. John seemed unchanged; harder perhaps, a bit gray, eyes darker. I saw him checkups, at the best restaurants, visiting his friends in the hospital. He said little, but always an embrace, kisses, and a look that flooded me. His eyes said, “Well, who? How long can I hold this debt?”

When I retired and left the state, I heard from John every Christmas. A succinct message, “Wishing you well. Always the ‘well.’” A decade after I left, John died, then almost immediately Louis, the part dying with the whole. The yearly card from John’s brother said thanks, but that wasn’t the end. The holiday cards continued from the brother, then from John’s son. After ten more years, I moved again and the cards stopped.

Every winter I wonder if this is the year they’ll find me again.

Larry Zaroff focused on cardiac surgery for 29 years, then spent the next 10 years concentrating on mountain climbing. In 2000 he received a 1963 from Stanford, where he currently teaches medical humanities. He also writes for the New York Times science section, works one day a week as a volunteer family doctor, and in 2006 was honored as Stanford’s Teacher of the Year. larry.zaroff@gmail.com
We see dead people: A failure of science and faith

Craig M. Klugman, PhD

Rational, scientific culture places an impermeable boundary between the living and the dead. In the United States, discussing someone who has died is socially acceptable for approximately six months after the death. Once that grieving period has elapsed, most Americans expect mourners to refrain from discussing the deceased. It is also considered aberrant for mourners to speak about feeling a presence, seeing a figure, or hearing footsteps. Socially, the time for such “mind tricks” has ended, and mourners are expected to accept that the deceased is no longer a part of the reality of everyday life. For “normal” people, the dead don’t talk to or with the living, the dead don’t intimately touch the living, and the dead certainly don’t hang around and warn the living of imminent danger. Science tells us that people who claim such experiences are delusional or experiencing abnormal griefing. Religion might tell us they’re being visited by demons.

Despite Americans’ strong denial of the possibility of interacting with the deceased, when Americans are surveyed by researchers, they report contact at surprising rates. Andrew Greeley found that 42% (619 of 1,473) of Americans in a national survey reported experiencing a post-death contact.1 In a 2006 random telephone survey, 97% (196 of 202) of Nevadans the researchers spoke to had experienced two or more post-death contacts such as sensing the presence of the deceased, feeling the touch of the deceased, or hearing the deceased. However, when asked whether they have a connection to the deceased, only 62.6% (127 of 202) said yes.2 Thus, in the Nevada study there was incongruence between having a haunting experience and naming it a haunting experience. The problem with research on rates of contact with the dead is that the people who are willing to talk about the topic are that minority which already has an interest. In the Nevada survey, 75% of people contacted refused to participate (609 out of 811 subjects). Whether they were uninterested, uncomfortable, or busy, we will never know.

The types of contact with the deceased reported by studies like these vary widely, from images, to touch, to signs and symbols. In my own research, cited above, the most common contact (reported by 87 percent of subjects) is a dream about the deceased which feels like a true visit. In 2001, I completed a qualitative study of 15 death-history interviews of subjects in the Houston-Galveston area. The experiences those interviewees reported were similar to those later found in the Nevada telephone survey. James had dreams about his deceased partner in which his husband explained his life in purgatory, and how later he moved on to heaven.3 Carol talked about feeling her grandmother as a protecting presence, keeping Carol safe from harm and from traffic accidents.4 Dena talked about her dead husband physically touching her ankle, a unique form of intimacy. Although she believes the experience is real, it has created a quandary for her because her religion states that the dead go to heaven, not her bed. Other subjects talked about windows opening or closing, televisions and radios mysteriously turning on and off, or even a certain song playing over and over on the radio or iPod. They know that these happenings are caused by the dead trying to communicate.5

As a result of my research interests, I’m often asked to speak with people who have had post-death contacts, or to help people explore their desires for post-death contact, outside of the research context. One time I was invited to join Mary and her friend, a self-proclaimed psychic, to talk about Mary’s recently deceased father. Mary’s friend suddenly stopped the conversation and stated, “Stop looking, there is nothing under the floor.” Mary admitted that her father had always told her that he hid money under the floor and so when he died, she went into his apartment and started tearing up the carpets. One Halloween, Vanessa invited me to use a Ouija board to contact her recently deceased father. During our session, the Ouija board spelled out “Little Yellow Bird.” I looked at her and said that these things never work or make sense. Vanessa started crying because “Little Yellow Bird” was the name she and her husband had for their dog. Another time, I comforted Trudy who was lamenting the loss of her husband on the nine month anniversary of his death. An observer to this conversation suddenly said “Sweet Muffin” and apologized because he had no idea where those words came from. Trudy stopped and smiled, later explaining that the phrase was a secret pet name she and her husband had for their dog.

Americans aren’t alone: hauntings by the deceased are a fairly common occurrence around the world. The Chinese have a particularly vicious form of contact with the dead, where a person who has been greedy in life becomes a “hungry ghost,” an entity that wanders around the world, sometimes causing illness or misfortune and other times stealing from tourists. The Hungry Ghost Festival, which is celebrated in August, is designed to placate these ghosts. In Bangladesh, the Durga Puja festival is held every year to honor the goddess Durga. It is believed that the goddess travels throughout the world, visiting various places and offering their inhabitants assistance. In Japan, the Obon Festival is held to honor the spirits of deceased ancestors. The festival is believed to bring together the spirits of the deceased and the living, allowing them to interact with one another. In India, the Diwali festival is celebrated to honor the goddess of wealth and prosperity. It is believed that the goddess travels throughout the world, visiting various places and offering their inhabitants assistance. In Guatemala, the Day of the Dead festival is held to honor the spirits of deceased ancestors. The festival is believed to bring together the spirits of the deceased and the living, allowing them to interact with one another.

(continued on next page)
In this era, Americans were more open about spiritual matters relating to death and had a broader view about what constituted an appropriate topic of scientific research. As the same time that most modern Americans discourage conversations about the dead and stigmatize individual reports of contact with the dead, collectively we’re also fascinated by them. Books written by mediums (John Edward, Allison DuBois, James Van Praagh, Sylvia Browne) are best-sellers, and television shows featuring mediums (John Edward’s Crossing Over, Medium, Ghost Whisperer) and movies about interactions with the deceased (The Others, The Sixth Sense, Ghost) are popular.

Contemporary U.S. culture simultaneously rejects, and is fascinated by, the possibility of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.11 “Hauntings” are a lived experience of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.