

THE GREAT PRETENDER

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PREFACE

The story that follows is true. It is also not true.

This is patient #5213's first hospitalization. His name is David Lurie. He is a thirty-nine-year-old advertising copywriter, married with two children, and he hears voices.

The psychiatrist opens the intake interview with some orienting questions: *What is your name? Where are you? What is the date? Who is the president?*

He answers all four questions correctly: *David Lurie, Haverford State Hospital, February 6, 1969, Richard Nixon.*

Then the psychiatrist asks about the voices.

The patient tells him that they say, "It's empty. Nothing inside. It's hollow. It makes an empty noise."

"Do you recognize the voices?" the psychiatrist asks.

"No."

"Are they male or female voices?"

"They are always male."

"And do you hear them now?"

"No."

"Do you think they are real?"

"No, I'm sure they're not. But I can't stop them."

The discussion moves on to life beyond the voices. The doctor and patient speak about Lurie's latent feelings of paranoia, of dissatisfaction, of feeling somehow less than his peers. They discuss his childhood as a son of two devout Orthodox Jews and his once intense relationship with his mother that had cooled over time; they speak about his marital issues and his struggle to temper rages that are sometimes directed at his children. The interview continues on in this manner for thirty minutes, at which time the psychiatrist has gathered nearly two pages of notes.

The psychiatrist admits him with the diagnosis of schizophrenia, schizoaffective type.

But there's a problem. David Lurie doesn't hear voices. He's not an advertising copywriter, and his last name isn't Lurie. In fact,

David Lurie doesn't exist.

The woman's name doesn't matter. Just picture anyone you know and love. She's in her mid-twenties when her world begins to crumble. She can't concentrate at work, stops sleeping, grows uneasy in crowds, and then retreats to her apartment, where she sees and hears things that aren't there—disembodied voices that make her paranoid, frightened, and angry. She paces around her apartment until she feels as if she might burst open. So she leaves her house and wanders around the crowded city streets trying to avoid the burning stares of the passersby.

Her family's worry grows. They take her in but she runs away from them, convinced they are part of some elaborate conspiracy to destroy her. They take her to a hospital, where she grows increasingly disconnected from reality. She is restrained and sedated by the weary staff. She begins to have "fits"—her arms flailing and her body shaking, leaving the doctors dumbstruck, without answers. They increase her doses of antipsychotic medications. Medical test after medical test reveals nothing. She grows more psychotic and violent. Days turn into weeks. Then she deflates like a pricked balloon, suddenly flattened. She loses her ability to read, to write, and eventually she stops talking, spending hours blankly staring at a television screen. Sometimes she grows agitated and her legs dance in crooked spasms. The hospital decides that it can no longer handle her, marking her medical records with the words TRANSFER TO PSYCH.

The doctor writes in her chart. Diagnosis: schizophrenia.

The woman, unlike David Lurie, does exist. I've seen her in the eyes of an eight-year-old boy, an eighty-six-year-old woman, and a teenager. She also exists inside of me, in the darkest corners of my psyche, as a mirror image of what so easily could have happened to me at age twenty-four, had I not been spared the final move to the psychiatric ward by the ingenuity and lucky guess of a thoughtful, creative doctor who pinpointed a physical symptom—inflammation in my brain—and rescued me from misdiagnosis. Were it not for that twist of fortune, I would likely be lost inside our broken mental health system or, worse, a casualty of it—all on

account of a treatable autoimmune disease masquerading as schizophrenia.

The imaginary “David Lurie,” I would learn, was the original “pseudopatient,” the first of eight sane, healthy men and women who, almost fifty years ago, voluntarily committed themselves to psychiatric institutions to test firsthand if doctors and staff could distinguish sanity from insanity. They were part of a famously groundbreaking scientific study that, in 1973, would upend the field of psychiatry and fundamentally change the national conversation around mental health. That study, published as “On Being Sane in Insane Places,” drastically reshaped psychiatry, and in doing so sparked a debate about not only the proper treatment of the mentally ill but also how we define and deploy the loaded term *mental illness*.

For very different reasons, and in very different ways, “David Lurie” and I held parallel roles. We were ambassadors between the world of the sane and the world of the mentally ill, a bridge to help others understand the divide: what was real, and what was not.

Or so I thought.

In the words of medical historian Edward Shorter, “The history of psychiatry is a minefield.” Reader: Beware of shrapnel.

PART ONE

*Much Madness is divinest Sense
To a discerning Eye
Much Sense—the starkest Madness
'Tis the Majority
In this, as all, prevail
Assent—and you are sane
Demur—you're straightway dangerous
And handled with a Chain*

—Emily Dickinson

MIRROR IMAGE

Psychiatry, as a distinct branch of medicine, has come far in its short life span. The field has rejected the shameful practices of the recent past—the lobotomies, forced sterilizations, human warehousing. Today’s psychiatrists boast a varied arsenal of effective drugs and have largely dropped the unscientific trappings of psychoanalytic psychobabble, the “schizophrenogenic” or “refrigerator” mothers of yesteryear who had been blamed for triggering insanity in their offspring. Two decades into the twenty-first century, psychiatry now recognizes that serious mental illnesses are legitimate brain disorders.

Despite all these advancements, however, the field lags behind the rest of medicine. Most of our major innovations—better drugs, improved therapies—were in play around the time we first walked on the moon. Though the American Psychiatric Association reassures us that psychiatrists are uniquely qualified to “assess both the mental and physical aspects of psychological problems,” they are, like all of medicine, limited by the tools at hand. There are not, as of this writing, any consistent objective measures that can render a definitive psychiatric diagnosis—no blood tests to diagnose depression or brain scans to confirm schizophrenia. Psychiatrists instead rely on observed symptoms combined with patient histories and interviews with family and friends to make a diagnosis. Their organ of study is the “mind,” the seat of personality, identity, and selfhood, so it should not be surprising that the study of it is more impenetrable than understanding, say, the biology of skin cancer or the mechanics of heart disease.

“Psychiatry has a tough job. In order to get the answers we

need, the truth about what's really going on, we need to understand our most complex organ, the brain," said psychiatrist Dr. Michael Meade. "To understand how this physical organ gives rise to the phenomenon of consciousness, of emotion, of motivation, all the complex functions we humans see as possibly distinguishing us from other animals."

Diseases like the one that set my brain "on fire" in 2009 are called the great pretenders because they bridge medical worlds: Their symptoms mimic the behaviors of psychiatric illnesses like schizophrenia or bipolar disorder, but these symptoms have known physical causes, such as autoimmune reactions, infections, or some other detectable dysfunction in the body. Doctors use terms like *organic* and *somatic* to describe diseases like mine, whereas psychiatric illnesses are considered *inorganic*, *psychological*, or *functional*. The whole system is based on this distinction, on categorizing illness as one or the other, and it dictates how we treat patients up and down the scale.

So what is mental illness? The question of how to separate sanity from insanity, of how to even define mental illness, rises above semantics, and above deciding what kind of specialist will care for you or your loved one during a time of intense need. The ability to accurately answer this question shapes everything—from how we medicate, treat, insure, and hospitalize to how we police and whom we choose to imprison. When doctors diagnosed me with an organic illness (as in physical, in the body, *real*) as opposed to a psychiatric one (in the mind, and therefore somehow *less real*), it meant that I'd receive lifesaving treatment instead of being cordoned off from the rest of medicine. This separation would have delayed or even derailed my medical team's efforts to solve the mystery in my brain and would have likely led to my disablement or death. The stakes couldn't be higher, yet, as psychiatrist Anthony David told me, "the lay public would be horrified to realize how flawed and arbitrary a lot of medical diagnosis is."

Indeed, this "flawed and arbitrary" diagnostic system has life-altering ramifications for the one in five adults living in the United States who will experience symptoms of mental illness this year. It even more urgently affects the 4 percent of Americans who contend with serious mental illness,¹ a segment of the population

whose lives are often shortened by ten to twenty years. Despite all of our medical progress—of which I’m a direct recipient—the sickest among us are getting sicker.

Even if you are one of the lucky few who have never questioned the firing of their synapses, this limitation touches you, too. It shapes how you label your suffering, how you square your eccentricities against the group, how you understand your very self. Psychiatrists, after all, were first known as alienists—a choice term that conveys a sense not only of the doctors’ outsider status from the rest of medicine and patients’ alienation from themselves, but also of being *the other*. “Insanity haunts the human imagination. It fascinates and frightens all at once. Few are immune to its terrors,” wrote sociologist Andrew Scull in his book *Madness in Civilization*. “It challenges our sense of the very limits of what it is to be human.” It’s undeniable: There is something profoundly upsetting about a person who does not share our reality, even though science shows us that the mental maps we each create of our own worlds are wholly unique. Our brains interpret our surroundings in highly specific ways—your blue may not be my blue. Yet what we fear is the unpredictability of a mentally ill “other.” This fear emerges from the sneaking realization that, no matter how sane, healthy, or normal we may believe we are, our reality could be distorted, too.

Before I turned twenty-four, all I’d really known of madness was from reading a stolen copy of *Go Ask Alice* in elementary school, or hearing about my stepfather’s brother who was diagnosed with schizophrenia, or averting my eyes as I passed a homeless person pawing at imaginary enemies. The closest I got to looking it in the eyes was when, as a tabloid reporter, I’d interviewed in prison a notorious sociopath, whose sharp wit made for great copy. Mental illness was cinematic: the genius mathematician John Nash, played by Russell Crowe in *A Beautiful Mind*, drawing equations on chalkboards, or a sexy borderline à la Angelina Jolie in *Girl, Interrupted*. It seemed almost aspirational, some kind of tortured but sophisticated private club.

And then my illness struck, the autoimmune encephalitis that would devastate me, briefly robbing me of my sanity and changing

my life. Sharp fragments of that time stay with me a decade later, slivers from my own memories, my family's stories, or my medical records: the early depression and flu-like symptoms, the psychosis, the inability to walk or talk, the spinal taps, the brain surgery. I remember vividly the imaginary bedbugs, which I believed had taken my apartment hostage; falling apart in the *New York Post* newsroom; nearly jumping out the window of my father's third-floor apartment; the nurses I was convinced were really undercover reporters come to spy on me; the floating eyes that terrified me in the bathroom; the belief that I could age people with my mind. I remember, too, the smug, dispassionate psychiatrist who had treated me in the hospital, calling me an "interesting case" and dosing me with what we would later learn were unnecessary amounts of antipsychotic medications. This was around the time that the medical team began to give up on my case, and the words *TRANSFER TO PSYCH* started to creep into my medical records.

My family, like many families before them, fought against the tyranny of the mental illness label. My parents were resolute: I was *acting* crazy, sure, but *I* was not crazy. There was a difference. I may have seemed violent, paranoid, and delusional, but I was sick. It wasn't *me*. Something had descended upon me in the same way that the flu or cancer or bad luck does. But when the doctors couldn't immediately find a physical cause, nothing concrete to pinpoint and treat like an infection or tumor, their lens shifted. They moved to a possible diagnosis of bipolar disorder, and then to schizoaffective disorder as my psychosis intensified. Given my symptoms, the psychiatrists' diagnoses made sense. I was hallucinating; I was psychotic; I experienced a cognitive decline. No other tests could explain the sudden change. They saw a bipolar patient. They saw a schizoaffective person. They were wrong. But in nearly any other case, they would have been "right."

Psychiatry is not the lone discipline to wander in such diagnostic haziness. The odds are high that in your lifetime, you will one day suffer from a disease whose causes and treatments are still unknown, or you will face a meaningful medical error that could delay proper treatment, hurt you, or contribute to the cause of your death. The list of illnesses without known cause and cure is long—from Alzheimer's disease to cardiac syndrome X to sudden

infant death syndrome. It has been estimated that a third of people who see their general practitioners will suffer from symptoms that have no known cause or are deemed “medically unexplained.” We don’t really know how everyday drugs like Tylenol work, nor do we really know what exactly happens in the brain during anesthesia, even though 250 million people go under every year.

Look at the role that greed, arrogance, and profit-motivated overprescription played in driving the opiate epidemic—it was common practice to prescribe highly addictive medications for pain until we realized the untold damage and death the drugs caused. Accepted dogma often goes through reappraisals.

Medicine, whether we like to admit it or not, frequently operates more on faith than certainty. We can, in some special cases, prevent diseases with vaccines (smallpox, polio, measles, for example), or with healthy living measures (by purifying our drinking water or quitting smoking) and preemptive scans (as is the case with prostate, breast, and skin cancers), but for the most part we are limited in our ability to actually *cure*.

Despite the shared uncertainties, psychiatry is different from other medicine in crucial aspects: No other discipline can force treatment, nor hold people against their will. No other field contends so regularly with a condition like anosognosia, whereby someone who is sick does not know it, requiring physicians to make difficult decisions about how and when to intervene. Psychiatry makes judgments about people—about our personalities, our beliefs, our morality. It is a mirror held up to the society in which it is practiced. One label applied on your medical record by one doctor could easily send you tumbling off into a whole different hospital with your psychiatric records segregated from the rest of your medical records.

Here was where my story diverged from those of so many other patients. Thanks to many lucky factors that helped set me apart—my age, race, location, socioeconomic situation, generous insurance coverage—doctors pushed for more tests, which led to a spinal tap that revealed the presence of brain-targeting autoantibodies. The doctors were confronted with tangible evidence that disproved their psychiatric diagnosis. My illness was now comfortably *neurological*. I had spinal fluid tests, antibody workups, and academic studies to back me up. Doctors could

provide a one-sentence explanation for what happened: My body attacked my brain. And there were solutions that could lead to improvement—even a cure. Hope, clarity, and optimism replaced the vague and distant treatment. No one blamed me or questioned if each symptom was real. They didn't ask about alcohol consumption or stress levels or family relationships. People no longer implied that the trouble was all in my head.

Mine became a triumphant story of medical progress, thanks to cutting-edge neuroscience. *This girl was crazy; now she is cured.* Medicine stands on a pedestal of stories like these—the father with stage four lung cancer who goes into full remission after targeted therapy; the infant who receives cochlear implants and will never have to know a world without sound; the boy with a rare skin disease who is saved by new skin grown from stem cells. Stories like these lend credence to the belief that medicine follows a linear path of progress, that we are only moving forward—unlocking mysteries of the body and learning more about the final frontiers of our minds on our way to cures for everyone.

I spent four years after my diagnosis collecting facts about my disease, about ages of onset, and about new advances in infusion treatments—a kind of armor to defend against the lonely irrationality of it all. *I am proof of our advancement.* Still, I am stalked by the everpresent threat that psychosis will return. Writing this now, halfway through my pregnancy with twins, I can't forget the ways my body can (and has) failed me. As traumatic as being diagnosed with melanoma was in my late teens, it did not feel like the disease touched *a part of my soul* the same way that my experience with psychosis did. Psychosis is the scariest thing that has ever happened to me. It was neurological, “organic,” but it came *from me*, from inside who I am, making it far scarier than any other “physical” illness. It rocked my sense of self, my way of seeing the world, my comfort in my own skin, and shook the foundations of who I am. No amount of fact-gathering could arm me against this truth: We are all hanging on by a very thin thread, and some of us won't survive our fall.

I published *Brain on Fire* to help raise awareness of my condition and in the aftermath was invited to lecture widely at medical schools and neurological conferences, spreading the word about my disease like a missionary, determined to make sure no

others were left undiagnosed. At one point, I had the chance to address a large crowd of psychiatrists inside a functioning psychiatric hospital. It was located in a renovated army barracks, but it felt light, white, and modern. *Like a real hospital*, I remember thinking. (When I had packed for the trip I made sure to bring my most adult, sophisticated, *not crazy* ensemble, a simple black-and-turquoise Ann Taylor shift dress paired with a crisp black blazer.)

After my presentation that day, a psychiatrist introduced himself to our group of presenters, speaking in soft but urgent tones about one of his patients. He had diagnosed a young woman with schizophrenia, but in his words, “It just didn’t feel right.” In fact, she reminded him of me. The woman was of a similar age, had a similar diagnosis, and exhibited similar symptoms. But she also appeared similar to the sea of others with serious mental illness who were being treated alongside her. The question was, How do we know the difference? How to decide who will respond to the intervention I received—the infusions that helped stop my body from fighting itself—versus psychiatric treatments? The group of doctors discussed next steps, the blood tests, lumbar punctures, and MRI scans that might offer an alternative diagnosis for this young woman. Later, as we walked through one of the hospital’s units, passing a group therapy meeting, I couldn’t help wondering, *Is she in there?*

I learned after my talk that the young woman had indeed tested positive for autoimmune encephalitis, the same disease I’d had. But because she had remained misdiagnosed for two years, unlike the single month I had spent in the hospital, she would probably never regain the cognitive abilities that she had lost. She could no longer care for herself in even the most basic ways and despite her successful diagnosis, she now would, one doctor told me, operate as a permanent child.

I had thought I was done examining my own story after I published my memoir. But once you’ve come face-to-face with real madness and returned, once you’ve found yourself to be a bridge between the two worlds, you can never turn your back again. I couldn’t shake the thought of the words TRANSFER TO PSYCH in my own medical records. What happened to this young woman almost happened to

me. It was like seeing my reflection through the looking glass. She was my could-have-been, my mirror image.

How are we—my mirror images and I—any different from the millions of people with serious mental illness? How could we be so easily misdiagnosed? What does mental illness mean, anyway, and why would one affliction be more “real” than another? These questions have haunted me ever since my memoir was released, when the stories of people’s battles within the medical system first landed in my inbox. Some write hoping to have my disease. Anything, some say, except mental illness.

One email I received was from the father of a thirty-six-year-old man who had struggled for two decades with debilitating psychosis. He told me how little modern medicine had been able to offer. “They seem to blame my son for his ‘psychiatric illness’ on the basis that he has no ‘physical illness’ that they can heal,” he wrote. The drugs, the only treatment offered, had not helped, but actually made him worse. Despite his family’s pleas for other options, the response was, “Take the drugs—or we’ll force him to take them.”

The father recognized his family’s plight in my own story and had been inspired by my parents’ successful pushback against the medical system. My recovery bolstered his determination to continue searching for more meaningful answers for his son. But something I’d said subsequently had troubled him. In his email he included a YouTube link to an event where I’d spoken at the release of the memoir’s paperback edition. As I watched the clip, I felt like I was being slapped in the face by my own palm. He quoted my words back to me: “My illness appeared as if it was a psychiatric condition, but it was *not* a psychiatric condition—it was a physical condition.”

This father felt betrayed hearing me utter the same unfair distinction that he so often heard from his son’s doctors. “The brain is a physical organ and physical disease occurs within the brain. Why does that make it a ‘psychiatric condition’ instead of a physical ‘disease’?” he wrote. “What am I missing?”

He was right, of course. How had I so wholeheartedly embraced the same unproven dichotomy that could have confined me to a psychiatric ward, or even killed me? Was it my need to believe that, because I had a physical disorder, I had been “cured”

in a way that set me apart from people with psychiatric conditions? What else had I—had *we*—accepted as fact that may have been dangerously reductive? How many fallacies about the mind and brain have we all just been taking for granted? Where did the divide lie between brain illness and mental illness, and why do we try to differentiate between them at all? Have we been looking at mental illness all wrong?

To answer this, I had to heed the advice that my favorite doctor, my own Dr. House, neurologist Dr. Souhel Najjar, often gives his residents: “You have to look backward to see the future.”

NELLIE BLY

New York, 1887

The young woman fixed her focus on the face, barely registering the wide, mournful eyes that stared back at her in the mirror. She smiled. She raged. She grimaced. She read aloud ghost stories until she spooked herself so thoroughly that she had to turn up the gaslight before she could return to the mirror. She practiced these hideous gazes until dawn, when she cleaned herself, put on an old, moth-eaten dress, and tried to tamp down the growing uncertainty about what lay ahead. There was a chance she would never come home, or that even if she did, this assignment could change her forever. “The strain of playing crazy,” she wrote, “might turn my own brain, and I would never get back.”

Despite her intense hunger, she skipped breakfast and headed to the Temporary Home for Females on Second Avenue. This morning she called herself Nellie Brown, though she had been born Elizabeth Jane Cochran, and as a professional journalist went by Nellie Bly. Her assignment, given to her by her editor at Joseph Pulitzer’s *New York World*, was to infiltrate the notorious Women’s Lunatic Asylum on Blackwell Island as a mental patient to write a “plain and unvarnished” first-person narrative about the conditions there. In order to get inside the Blackwell Island asylum, after all, she would need to “prove” that she was indeed insane. This was why she had forced herself to stay up all night, hoping that the physical strain of the sleep deprivation, combined with her disheveled appearance and wild eyes, might induce the house’s matron to call the authorities to whisk Nellie off to an asylum, setting the whole plan in motion.

When the US government started tracking the incidence of mental illness, it broke it down into two broad categories of “idiocy” and “insanity.” By 1880, the census had expanded to include seven categories of mental disease (mania, melancholia, monomania, paresis, dementia, epilepsy, and dipsomania), but in the first half of the nineteenth century most doctors believed that craziness was one-size-fits-all, something called unitary psychosis. If you acted crazy, you were crazy.

Almost anything could make you a ward of the state. “Compulsive epilepsy, metabolic disorders, syphilis, personality due to epidemic encephalitis, moral adverse conditions such as: loss of friends, business troubles, mental strain, religious excitement, sunstroke, and overheat,” read one intake log from California’s Patton State Hospital archive. One reason for commitment at Patton State in the nineteenth century was excessive masturbation. Another was for being “kicked in the head by a mule.” Other hospital records show that some poor souls were committed for “habitual consumption of peppermint candy” or “excessive use of tobacco.” Unmoored after a child died? You could be institutionalized. Use a foul word or two? In a cell you go. Miss a menstrual cycle and you could be committed. These kinds of convenient diagnoses, the sort given to citizens who don’t conform, have littered the annals of psychiatry. Hysteria was lobbed at women who dared defy social mores. In England, militant suffragettes, in particular, were diagnosed with “insurgent hysteria.” A nineteenth-century Louisiana physician outlined two “conditions” unique to the slaves he studied: *dysaesthesia aethiopica*, or pathological laziness; and *drapetomania*, the (evidently inexplicable) desire to escape bondage. Treatments for both included whippings. These were not, in any medical or scientific sense, real illnesses or disorders—they were pseudoscience, purely societal strictures posing as medicine.

Throw a rock into a crowd in the late 1800s, and there’s a good chance you’d hit someone who had spent some time in an asylum. And, for those who did end up committed, odds weren’t great that they would make it out intact. Once declared insane, you could permanently lose custody of your children, property, and rights to inheritance. Many would remain locked away for a long time, if not the rest of their lives. Those who pushed back often were

beaten or “treated” with bleeding, leeching, enemas, and induced bouts of intense vomiting (which were key parts of general medicine’s arsenal of care at the time). A substantial portion of people admitted to psychiatric hospitals in this period died within months, even weeks, of being admitted—though there is no definitive proof whether this is because they really suffered from misdiagnosed life-threatening medical conditions or whether the hospitals’ conditions themselves led to an early end, or if it was a combination of the two.

The malleability of the era’s definitions of insanity meant that any man of a certain means and pedigree could just pay off a doctor or two and dispatch whomever he wanted gone, a disobedient wife, for example, or an inconvenient relative. This understandably bred a widespread anxiety over false diagnoses. Newspapers stoked this fear by publishing a litany of articles about people sidelined into mental hospitals who weren’t truly sick.

There was Lady Rosina, an outspoken British writer whose feminist views estranged her from her famous husband, writer Sir Edward Bulwer-Lytton (creator of the most clichéd opening line of all time: “It was a dark and stormy night”). Sir Bulwer-Lytton didn’t have time for such a mouthy wife, especially with his seat in Parliament in jeopardy, so he tried to lock her up to shut her up. Thanks to her own celebrity and the pressure that the press put on her husband, she emerged three weeks later and wrote about her experience in 1880’s *A Blighted Life*. “Never was a more criminal or despotic Law passed than that which now enables a Husband to lock up his Wife in a Madhouse on the certificate of two medical men, who often in haste, frequently for a bribe, certify to madness where none exists.”

Elizabeth Packard continued Lady Rosina’s fight in America. Packard butted heads with her Presbyterian minister husband, Theophilus, about her interest in spiritualism. Her religious interests made Packard a direct threat to her husband’s stature in the community, so to save his own reputation he recruited a doctor to denounce her as “slightly insane” and commit her to Jacksonville Insane Asylum, where she lived for three years. When Packard was released into her husband’s care, she managed to escape the room he had locked her in by dropping a note out of the window. This note reached her friend, who arranged for a group of

men to request a writ of habeas corpus on her behalf, giving Packard the opportunity to defend her sanity in court. A jury deliberated for only seven minutes before concluding that, despite what her husband and doctors said, Packard was sane. She published the book *The Prisoners' Hidden Life*, which also featured the experiences of other women unloaded into hospitals by their loved ones. Thanks to her work, the state of Illinois passed a "Bill for the Protection of Personal Liberty," which guaranteed that all who were accused of insanity would be able to defend themselves in front of a jury—since doctors, it was recognized, could be bought and sold. (There were negatives to Packard's reforms, as jurors could be grossly ignorant about matters related to mental illness.)

After Bly successfully made enough of a scene at the boardinghouse for the police to be summoned, she was escorted to Manhattan's Essex Market Police Court, where she faced the judge who would decide whether or not she should be locked up. Lucky for her, or rather for the *New York World*, the judge accepted the events of the morning at face value.

"Poor child," mused Judge Duffy, "she is well dressed, and a lady... I would stake everything on her being a good girl." Though she'd worn her most ragged clothes and acted as insane as she could, her genteel looks and manners made it hard for him to take the next step. The judge understood that Blackwell Island was far from a place of refuge, and he hesitated to send someone he felt was too well bred to suffer the indignities there. "I don't know what to do with the poor child," the judge said. "She must be taken care of."

"Send her to the Island," suggested one of the officers.

The judge called in an "insanity expert," a colloquial term from the era to describe the doctors who chose to work with the insane. These specialists, also called alienists and medical psychologists, or mocked as "bughouse doctors," "quacks," or "mad doctors," mainly spent their careers confined, like their charges, to asylums. (*Psychiatrist* would become the preferred term in the early twentieth century.)

The insanity expert asked Bly to say "ah" so he could see her tongue. He shined a light into her eyes, felt her pulse, and listened to the beating of her heart. Bly held her breath. "I had not the least

idea of how the heart of an insane person beat,” she later wrote. Apparently her vital signs spoke for her: On whatever quantitative grounds he found to set her apart from the sane, the expert took her to the insane ward at Bellevue. There she was examined by a second doctor who deemed her “positively demented” and shipped her off to Blackwell Island.

When Bly stepped off the boat and onto the shore, the whiskey-soaked attendant welcomed her to the women’s asylum: “An insane place, where you’ll never get out of.”

The word *asylum* comes from an ancient Greek word meaning “safe from being seized” (by, say, a Homeric warrior). Among the Romans, the word evolved to its current meaning—“a place of refuge” or “a place safe from violence.” The first asylums built specifically to house the mentally ill emerged in the Byzantine Empire around AD 500, and by the turn of the new millennium many towns in Europe, the Middle East, and the Mediterranean had one. As forward thinking as that seems, hospitals as we know them today are a modern concept. In the early days, there weren’t many differences among jails, poorhouses, and hospitals, and these “asylums” were known for their brutal treatment of their charges.

The vast majority of the mentally ill lived with their families, but this, too, sounds more idyllic than the reality. In eighteenth-century Ireland, mentally ill family members were held in holes five feet beneath their cottage floors, a space not big enough for most to stand up, with a barrier over the hole to deter escape. (“There he generally dies.”) The rest of Europe around that time was no more progressive. In Germany, a teenager suffering from some unnamed psychological affliction was chained up in a pigpen for so long that he lost the use of his legs; in England, the mentally ill were staked to the ground in workhouses; in one Swiss city, a fifth of the mentally ill were under constant restraint at home.

Europe’s oldest psychiatric hospital, Bethlem Royal Hospital (nicknamed “Bedlam”), started as a priory in London in 1247 and was a hospital in the medieval sense: a charitable institution for the needy. Bethlem began catering exclusively to the insane about a century later; their idea of a cure was to chain people in place and whip and starve them to punish the disease out of their systems. One person, confined to Bethlem for fourteen years, was held by a “stout iron ring” around his neck with a heavy chain that

was attached to the wall, allowing him to move only a foot. The belief then was that the insane were no better than animals and should be treated even worse because, unlike livestock, they were useless.

In the mid-1800s, American activist Dorothea Dix deployed her sizable inheritance to devote herself to these issues with a fierceness of purpose that hasn't been matched since. She traveled more than thirty thousand miles across America in three years to reveal the brutalities wrought upon the mentally ill, describing "the saddest picture of human suffering and degradation," a woman tearing off her own skin, a man forced to live in an animal stall, a woman confined to a belowground cage with no access to light, and people chained in place for *years*. Clearly, the American system hadn't improved much on Europe's old "familial" treatments. Dix, a tireless advocate, called upon the Massachusetts legislature to take on the "sacred cause" of caring for the mentally unwell during a time when women were unwelcome in politics. Her efforts helped found thirty-two new therapeutic asylums on the philosophy of moral treatment. Dorothea Dix died in 1887, the same year that our brave Nellie Bly went undercover on Blackwell Island, in essence continuing Dix's legacy by exposing how little had truly changed.

Blackwell Island was supposed to have been different. Built as a "beacon for all the world," it was located on 147 acres in the middle of the East River and was meant to embody the theory of moral treatment that Dix had championed. Its central tenets came from French physician Philippe Pinel, who is credited with breaking his charges free of their chains (literally) and instating a more humanistic approach to treating madness—though his legacy, historians suggest, comes more from myth than reality. "The mentally sick, far from being guilty people deserving of punishment, are sick people whose miserable state deserves all the consideration that is due to suffering humanity," Pinel said.

Connecticut physician Eli Todd introduced moral treatment Stateside and outlined the new necessities: peace and quiet, healthy diet, and daily routines. These new "retreats" replaced the old "madhouses" or "lunatickhouses" and moved to soothing surroundings away from the stresses of the city. In some cases, asylums expanded into mini-cities, where hospital

superintendents, doctors, and nurses lived alongside patients. They tended farms together, cooked in the kitchen together, even made their own furniture and ran their own railroads. The idea was that orderly routines and daily toil created purpose and purpose created meaning, which led to recovery. The doctor-patient relationship was key. People were treated as people, and the sick could be cured.

That was the intention, anyway. Blackwell Island may have been founded on these ideals in 1839, but by Nellie's era it had thoroughly earned its notoriety as one of the deadliest asylums in the country. After Charles Dickens visited in 1842, he immediately wanted off the island and its "lounging, listless, madhouse air." (Dickens later tried to commit his wife, Catherine, to an asylum so that he could pursue an affair with a younger actress—a downright monstrous act considering what he knew of these places.) Blackwell's asylum housed numbers that far exceeded its capacity. In one instance, six women were confined to a room meant for one. Reports detailed "the onward flow of misery," including a woman made to give birth in a solitary cell alone *in a straitjacket*, and another woman who died after mistaking rat poison for pudding.

The inhabitants Bly encountered on Blackwell Island looked lost and hopeless; some walked in circles, talking to themselves; others repeatedly insisted that they were sane but no one listened. Bly, meanwhile, dropped all pretense of insanity once she made it inside the hospital: "I talked and acted just as I do in ordinary life. Yet strange to say, the more sanely I talked and acted, the crazier I was thought to be," she wrote. Any worry—which would soon turn to hope—that she might be exposed as a fake evaporated the minute the nurses plunged her into an ice bath and scrubbed her until her goosefleshed skin turned blue, pouring three buckets of water over her in succession. She was so caught by surprise that she felt she was drowning (a similar sensation, I imagine, to waterboarding). "For once I did look insane," she said. "Unable to control myself at the absurd picture I presented, I burst into roars of laughter."

The first day, she quickly learned what it was like to be discarded by humanity. Whatever ladylike manner had caught the judge's eye was meaningless here, where she was just another in a

series of worthless paupers. Patients—even those with open syphilitic sores—were made to wash in the same filthy bathtub until it became thick and dirty enough with human waste and dead vermin that the nurses finally changed it. The food was so rotten that even butter turned rancid. The meat, when offered, was so tough the women chomped down on one end and pulled at the other with both hands to rip it into digestible pieces. Bly had too much decorum to discuss this in her article, but even using the toilets was a traumatic experience. They were long troughs filled with water that were supposed to be drained at regular intervals—but, like everything else on this godforsaken island, what was supposed to happen rarely did.

Bly listened to the stories from her sisters on Hall 6. Louise Schanz, a German immigrant, had landed in this hell simply because she couldn't speak English. "Compare this with a criminal, who is given every chance to prove his innocence. Who would not rather be a murderer and take the chance for life than be declared insane, without hope of escape?" Bly wrote.

Another patient told Bly about a young girl who had been beaten so badly by the nurses for refusing a bath that she died the next morning. One of the "treatments" used on the island was "the crib," a terrifying contraption in which a woman was forced to lie down in a cage so confining that it prevented any movement—like a tomb.

Within a few days, Bly had gathered more than enough evidence for her exposé, but now she began to worry that she would never be free. "A human rat trap," she called it. "It is easy to get in, but once there it is impossible to get out." This was not much of an exaggeration. According to an 1874 report, people spent on average ten to thirty years on Blackwell Island.

By this point, Bly was proclaiming her sanity to anyone who would listen, but the "more I endeavored to assure them of my sanity the more they doubted it."

"What are you doctors here for?" she asked one.

"To take care of the patients and test their sanity," the doctor replied.

"Try every test on me," she said, "and tell me am I sane or insane?"

But no matter how much she begged to be reevaluated, the

answer remained the same: “They would not heed me, for they thought I raved.”

Thankfully, after ten days with no word from Bly, her editor sent a lawyer to spring her from the rat trap. Safely back in Manhattan, Bly filed a two-part illustrated exposé—the first called “Behind Asylum Bars,” and the second “Inside a Madhouse”—published in the *New York World* in 1887. The article was syndicated across the country, horrifying the public and forcing politicians to do something about it. The Manhattan DA convened a grand jury to investigate and Bly testified, leading jurors on a tour of the island, which had been rapidly scrubbed into shape. But there was only so much Blackwell Island could cover up. In the end, thanks to this young reporter’s courage, the Department of Public Charities and Corrections agreed to a nearly 60 percent increase in the annual budget for care of the inmates.

If Bly’s publisher hadn’t intervened, how long would she have been confined on the island? And what of the other women still trapped inside? The line between sanity and insanity was far less scientific, less quantifiable than anyone wanted to admit. An op-ed in the *New York World* wrote that Bly’s exposé showed that “these experts cannot really tell who is and who is not insane,” which raised the question of “whether the scientific attainments in mental diagnosis possessed by the doctors who saw her amount to anything or not.”

The truth is, at this point in the nineteenth century, alienists still didn’t know what to do with the hordes of people filling their asylums. Unsurprisingly, the rest of medicine had no use for these “insanity experts,” who seemed to have no expertise in anything. A few years before Bly went undercover, Louis Pasteur had successfully demonstrated the germ theory of disease, leading to the discovery of vaccines against cholera and rabies, which revolutionized medicine by introducing the concept of prevention. In the span of a few decades, medical science had largely dropped the harmful practice of bloodletting and had (decades before Bly’s hospitalization) identified leukemia as a blood disorder, helping to launch the new field of pathology. The invisible had at once become visible as medicine bounded into the next century. Yet the

alienists, still blind, had only their asylums, cruel “crib” contraptions, and no solid theory about how to explain any of it.

Other than some money being thrown at the problem, nothing changed after Bly’s exposé. (As we will see, that would take a much larger mortar shell landing in the heart of psychiatry, nearly a century later.)

One of the most sophisticated and moneyed cities in the world, now aware of such cruelty visited upon its citizens, simply shrugged.

As we still do.

THE SEAT OF MADNESS

Today Blackwell Island no longer exists. In 1973, the island was renamed after Franklin D. Roosevelt, and the site where Bly spent her ten harrowing days is now home to a luxury condo development. But the kind of anguish she witnessed there doesn't just disappear. The questions she was trying to answer—questions about what it means to be sane, or insane, what it means to care for a suffering human being who often scares us—remain.

Madness has been dogging humanity for as long as humans have been able to record their own history. But the answer to what *causes* it—where it can be located, in a manner of speaking—has eluded us just as long. The explanation has ping-ponged throughout history among three players: mind/soul, brain, and environment. First, it was believed to be supernatural, a direct effect of meddling by the gods or devils. Thanks to unearthed skulls dated to around 5000 BC, we know that one of the earliest solutions was to bore holes in the head to release the demons that had presumably taken up residency there, a procedure called trephining. Another way to rid oneself of inner demons was to sacrifice a child or an animal so that the evil spirit could trade one soul for another. Early Hindus believed that seizures were the work of Grahi, a god whose name translates quite literally to “she who seizes.” The ancient Greeks believed that madness descended on them when their gods were angry or vengeful—a belief that continued on with the teachings of Judaism and Christianity. Lose faith or become too prideful and “the Lord shall smite thee with madness,” the Old Testament warned. In the book of Daniel, God punishes Nebuchadnezzar (“those who walk in pride he is able to

abase”) by deploying a form of madness that transforms him into a raving beast, stripping away his human capacity for rational thought. Exorcisms, ritualistic torture, and even burnings at the stake were some of the approaches employed to release the devil in unquiet minds. Those who survived suicide attempts—seen as an act spurred on by the devil himself—were dragged through the streets and hanged.

Enlightenment thinkers reshaped madness into irrationality and began to think of it as a by-product of the breakdown of reason rather than an outcome of demonic possession. René Descartes argued that the mind/soul was immaterial, inherently rational, and entirely distinct from our material bodies. Though religion clearly still played a role in this thinking, this dichotomy allowed madness to become “unambiguously a legitimate object of philosophical and medical inquiry,” wrote Roy Porter in *Madness: A Brief History*.

This area of medical inquiry got a name in 1808: *psychiatrie*, coined by German physician Johann Christian Reil. The new medical specialty (which should attract only the most forward-thinking practitioners, Reil wrote) would treat mind and brain, soul and body—what is today called the holistic approach. “We will never find pure mental, pure chemical, or mechanical diseases. In all of them one can see the whole,” Reil wrote. The principles he laid out then are as relevant today: Mental illnesses are universal; we should treat people humanely; and those who practice should be medical doctors, not philosophers or theologians.

Reil’s version of psychiatry didn’t deter the many doctors who chased promises of finding the “seat of madness.” What causes it? they wondered. Is there one area or hosts of them? Can we be driven to it by circumstance and environment, or is it rooted solely in the organs within our skulls? Alienists began to target the body, expecting that madness could be isolated and targeted—creating some truly horrific treatments along the way, from spinning chairs (developed by Charles Darwin’s grandfather Erasmus Darwin) that induced vertigo and extreme vomiting that was believed to lull the patient into a stupor; to “baths of surprise,” where floors fell away, dropping people into cold water below to shock the crazy out. As brutal as these treatments were, they were considered a step forward: At least we weren’t attributing cause to devils and

demons anymore.

An early practitioner named Benjamin Rush, a signer of the Declaration of Independence, believed that the cause of madness was seated in the brain's blood vessels. This prompted him to dream up some deranged treatments, including the "tranquilizing chair" (a case of the worst false advertising ever), a terrifying sensory-deprivation apparatus in which patients were strapped down to a chair with a wooden box placed over their heads to block stimulation, restrict movement, and reduce blood to the brain. Patients were stuck in this chair for so long that the seat was modified to include a large hole that could serve as a toilet. The insane weren't just neglected and ignored; they were abused and tortured—the "otherness" of mental illness making them fair game for acts of outright sadism.

The invention of the microscope led to descriptions of the contours of the brain and nervous system on the cellular level. In 1874, German physician Carl Wernicke pinpointed an area of the brain that, when damaged, created an inability to grasp the meaning of spoken words, a condition called Wernicke's aphasia. In 1901, Frankfurt-based Dr. Alois Alzheimer treated a fifty-one-year-old woman with profound symptoms of psychosis and dementia. When she died in 1906, Alzheimer opened up her skull and found the cause: plaque deposits that looked like tangled-up sections of fibrous string cheese. So: Was her mental illness caused by nothing more than an unfortunate buildup?

The greatest triumph came from the study of syphilis, a disease all but forgotten today (though seeing a resurgence¹) that surfaced around 1400. The famous people suspected to have had syphilis could crowd a Western civilization Hall of Fame: Vincent van Gogh, Oscar Wilde, Friedrich Nietzsche, Henry VIII, Leo Tolstoy, Scott Joplin, Abraham Lincoln, Ludwig van Beethoven, and Al Capone.

Stories of "the most destructive of all diseases" have abounded since the late Middle Ages. Doctors later called it the "general paralysis of the insane"—a group of doomed patients that made up an estimated 20 percent of all male asylum admissions in the early twentieth century. These patients staggered into hospitals manic and physically off-balance. Some under grand delusions of wealth spent all their money on ridiculous items like fancy hats. Their

speech sounded spastic and halting. Over the course of months or years, they would waste away, lose their personalities, memories, and ability to walk and talk, spending their final days sectioned off to the back wards of some local asylum until death. Patient histories, when available, revealed a pattern: Many of these men and women had developed syphilis sores earlier in their lives. Could this sexually transmitted disease be a latent cause of madness?

The answer came when two researchers identified spiral-shaped bacteria called *Spirochaeta pallida* in the postmortem brains of those of the insane with general paralysis. Apparently, the disease could lie dormant for years, later invading the brain and causing the constellation of symptoms that we now know of as tertiary syphilis. (Syphilis would come to be called the great pox, the infinite malady, the lady's disease, the great imitator, and the great masquerader—one more example of the great pretender diseases, because it could look like a host of other conditions, including insanity.) This was, as contemporary psychologist Chris Frith described, a “kind of peeling of the diagnostic onion.” We had parsed out something we thought generally of as “insanity” as having a physical cause. And the best part was that we could eventually cure it if we caught it early enough, too.

(Though they have different causes, the symptoms of syphilis share many similarities with those of autoimmune encephalitis, the disease that struck me, which I guess could give autoimmune encephalitis the dubious honor of being the syphilis of my generation.)

The more we learned about the science of the mind, the hazier the boundary between neurology and psychiatry became. During the twentieth century, neurology broke off into a distinct branch of medicine, and in doing so “claimed exclusive dominion over the organic diseases of the nervous system”—like stroke, multiple sclerosis, and Parkinson's. Meanwhile, psychiatrists took on the ones “that could not be satisfactorily specified by laboratory science”—like schizophrenia, depression, and anxiety disorders. Once a biological breakthrough was achieved, the illness moved out of psychiatry and into the rest of medicine. Neurologists work to uncover how damage to the brain impairs physical function; psychiatrists are there to understand how this organ gives rise to

emotion, motivation, and the self. Though the two fields overlap considerably, the separation embodies our mind/body dualism—and this continues today.

Clearly, syphilis and Alzheimer's disease weren't the only causes of insanity. In order to track down and cure the others—if they could be found—psychiatrists still needed to develop a diagnostic language that could help pinpoint the different types (which would hopefully lead to the cleaving out of different causes) of mental illness.

German psychiatrist Emil Kraepelin had been tackling this issue since the late nineteenth century, and though you've likely never heard of him, his work has had more influence on the way psychiatry is practiced today than did the famous Sigmund Freud, born the same year: 1856. The son of a vagabond actor / opera singer / storyteller, Kraepelin dedicated his life to organizing mental illnesses into orderly parts, perhaps as a reaction to such an unorthodox father. In doing so he endowed the nascent field with a new nosology, or system of diagnosis, that would later inspire the *Diagnostic and Statistical Manual of Mental Disorders*, the bible of psychiatry today. Kraepelin studied thousands of cases and subdivided them, breaking down what was described as “madness” into clear categories with varied symptoms as best he could. This culminated in the description of the medical term *dementia praecox*. Kraepelin defined *dementia praecox* in his 1893 textbook *Psychiatrie* as an early onset permanent dementia, a biological illness that caused psychosis and had a deteriorating course with little hope to improve, causing “incurable and permanent disability.” Kraepelin separated *dementia praecox* patients from those with “manic-depressive psychosis,” a disorder of mood and emotion that ranged from depression to mania, which had a better long-term prognosis. This division continues today with schizophrenia (and its component parts) and bipolar disorder (and its component parts). (In 1908, almost two decades after Kraepelin presented the diagnosis *dementia praecox* to the public, Swiss psychiatrist Paul Eugen Bleuler tested out the new term *schizophrenia*, which translates to “splitting of the mind,” contributing to a long-running confusion² over the term. Later, psychiatrist Kurt Schneider further defined schizophrenia with a list of “first rank symptoms” that include auditory hallucinations, delusions, and

or haphazard or accidental or meaningless in anything we do,” wrote Janet Malcolm in *Psychoanalysis: The Impossible Profession*.

And who wouldn't want this kind of careful attention and promise of a cure over the dour inevitability that the biological side (à la Emil Kraepelin) was offering? Consider the two differing interpretations of a patient's story as analyzed by both Kraepelin's followers and Freud. In 1893, fifty-one-year-old German judge Daniel Paul Schreber started to become obsessed with the idea that to save the world, he needed to become a woman and give birth to a new human race. He blamed these disturbing thoughts on his psychiatrist, whom he called a “soul murderer” who had implanted these delusions via “divine rays.” Doctors diagnosed Schreber with Kraepelin's dementia praecox and committed him to a psychiatric hospital, where he eventually died. When Freud read Judge Schreber's account, *Memoirs of My Nervous Illness*, he suggested that, instead, Schreber's behaviors stemmed from repressed homosexual impulses, not from an incurable brain disease. Treat the underlying conflict and you'd treat the person. If you had your choice, which kind of treatment would you pick? Americans overwhelmingly chose Freud, and Kraepelin and his acolytes were forsaken to the professional boondocks.

By the 1970s, nearly every tenured professor in psychiatry was required to train as an analyst, and most textbooks were written by them, too. Overnight, it seemed, analysts got “a power, a secular power, that they never had before and they never had since,” psychiatrist Allen Frances told me. You no longer went to your priest or parents; you paid an analyst to shrink you. Now “mind doctors” wanted to mine your “family relations, cultural traditions, work patterns, gender relations, child care, and sexual desire.” Psychiatrists were thrilled to leave the back wards of mental hospitals, where difficult patients had few options for cures, and instead to retrain as analysts and cater lucrative talk therapy treatments (five days a week!) to help the so-called worried well who suffered from a case of nerves brought on by modern life. The people who needed help the most were left behind as analysts comfortably cherry-picked their patients—mostly wealthy, white, and not very sick.

Americans jumped on the couch, embracing the “blank screens” of their therapists and the idea that the mind could be

improved. Decades after his death, Freud's method was suddenly everywhere: in women's magazines, in advertising (Freud's nephew Edward Bernays is called the father of public relations); even the CIA started snatching up analysts. America's second-biggest bestseller after the Bible became Dr. Benjamin Spock's *The Common Sense Book of Baby and Child Care*, which was based on Freudian theories. Another huge book of the moment was Norman O. Brown's *Life Against Death: The Psychoanalytic Meaning of History*, which attempted to reframe the past through a Freudian battle between freedom and repression. Hollywood hired psychiatrists on retainer on movie sets. Insurance companies paid for months of talk therapy and reimbursed at levels equal to other serious medical procedures.

No matter how many psychiatrists enlisted, however, there still weren't enough. By 1970, despite the influx of doctors, the demand exceeded the supply. Unlike the custodians of the sick in the past, psychoanalysts now promised to listen to their patients. In the best cases, patients found clarity and meaning from this relationship. Instead of pathologizing people outright, analysts saw each patient as unique in her psychic suffering. They gave us a deeper understanding of how fraught and layered our interior lives are: the complexities of sexuality; the key role that our childhoods play in our adult lives; how the unconscious speaks to us through our behaviors. Through the "interchange of words between patient and physician," as Freud put it, you could explore, comprehend, and even heal the sick parts inside us. "Words were originally magic, and the word retains much of its old magical powers even today," Freud wrote in 1920. "Therefore let us not underestimate the use of words in psychotherapy."³

One of the varied downsides was that doctors enacted vivid blame games on their patients (and the families of their patients), especially on mothers. (See the *refrigerator mother* [lack of maternal warmth] and the *schizophrenogenic mother* [an overbearing, nagging, domineering female, usually paired with a weak father], both of whom were believed to create symptoms of schizophrenia and autism in their children.) Viennese psychoanalyst Bruno Bettelheim,⁴ "psychoanalyst of vast impact," in *The Empty Fortress* in 1967 compared the family structure of those with mental illness,

especially autism, to concentration camps, a particularly damning argument because Bettelheim himself had survived two years in Dachau and Buchenwald. The only way one could recover was to completely sever relationships with family.

But what you didn't get with Freud was a focus on diagnosis. In fact, his followers practiced "extreme diagnostic nihilism." Nomenclature, shared diagnostic language—these didn't really matter to the analysts. In fact, psychiatrists expanded the scope of social deviance, pathologizing almost everyone in the process, effectively closing the chasm between sanity and insanity by showing that "true mental health was an illusion," as anthropologist Tanya Marie Luhmann wrote in her study of the profession *Of Two Minds*. According to a now infamous 1962 Midtown Manhattan study based on two-hour interviews with sixteen hundred people in the heart of the city, only 5 percent of the population were deemed mentally "well." The whole world was suddenly crazy, and psychiatrists were their caped crusaders.

America was again starting to look a lot like it had in the time of Nellie Bly—where anyone could be and often was (mis)diagnosed.

And then, in February 1969, "David Lurie" walked into the intake room at an unspecified hospital in Pennsylvania and set off a metaphorical bomb. He finally proved what so many people had long suspected: Psychiatry had too much power and didn't know what the hell to do with it.

ON BEING SANE IN INSANE PLACES

I often imagine Bly's trip back to Manhattan aboard the transport ferry from Blackwell Island—the air whipping her hair, the foul smells of the river, the buzzy relief—as her thoughts turned to the women she had abandoned.

“For ten days I had been one of them. Their sorrows were mine, mine were theirs, and it seemed intensely selfish to accept freedom while they were in bondage,” Bly wrote. “I left them in their living grave, their hell on earth—and once again I was a free girl.”

That was exactly how I felt every time I thought about my mirror image, and all those who had not been saved as I had—the others whom psychiatry had left behind.

A month or two after my presentation at the psychiatric hospital, I had dinner with Dr. Deborah Levy, a McLean Hospital psychologist who studies (among other things) genes that appear to put people at risk for developing serious mental illness, and her colleague Dr. Joseph Coyle, a McLean Hospital psychiatrist who is one of the foremost experts on the NMDA receptor, a part of the brain that is tampered with in the illness that struck me. (Tracking two neuroscience researchers in conversation is much like following an intense hockey game. Take your eye off the puck for one second, and you're lost.) We spoke about the hysterias of the past and the conversion disorders of the present; about the difference between malingering and Munchausen syndrome. The former describes faking an illness for some kind of gain (to win a lawsuit, for example), while the latter is the name of a mental disorder in

which one pretends to be sick when there isn't any obvious incentive. (The famous case of Gypsy Rose Blanchard is an extreme example of Munchausen *by proxy*, when you make someone else sick, often a child.) We talked a bit about the great pretender illnesses that blur the boundary between psychiatry and neurology and how hard it is for physicians to parse those out and about how my disease appeared to be a bridge between the two worlds, a "physical" disorder that masked itself as a "psychiatric" one.

I chimed in with the story I had recently learned of my mirror image. There shouldn't have been any difference between us; she should have received the same treatment, she should have had the same quick and urgent interventions, and she should have had the opportunity to recover as I had. But she had been derailed because of one crucial difference: Her mental diagnosis had stuck. Mine hadn't. Sympathetic, Dr. Levy asked me if I had ever heard of the study by Stanford professor David Rosenhan.

"Do you know it? The one where the people purposefully faked hearing voices and were admitted to psychiatric hospitals and diagnosed with schizophrenia?" she asked.

Nearly fifty years after its publication, Rosenhan's study remains one of the most reprinted and cited papers in psychiatric history (despite being the work of a psychologist rather than a psychiatrist). In January 1973, the distinguished journal *Science* published a nine-page article called "On Being Sane in Insane Places," whose driving thesis was, essentially, that psychiatry had no reliable way to tell the sane from the insane. "The facts of the matter are that we have known for a long time that diagnoses are often not useful or reliable, but we have nevertheless continued to use them. We now know that we cannot distinguish insanity from sanity." Rosenhan's dramatic conclusions, backed up for the first time by detailed, empirical data and published by *Science*, the sine qua non of scientific journals, were "like a sword plunged into the heart of psychiatry," as an article in the *Journal of Nervous and Mental Diseases* observed three decades later.

Rosenhan, a professor of both psychology and law, had posed this opening salvo: "If sanity and insanity exist, how shall we know them?" Psychiatry, it turned out, didn't have an answer—as it hadn't for centuries. This study "essentially eviscerated any vestige of legitimacy to psychiatric diagnosis," said Jeffrey A.

narrative as this to end up in *Science*, one of the most widely read peer-reviewed academic journals in the world, endowed with seed money from Thomas Edison and later Alexander Graham Bell. (*Science*'s most famous papers include the first time the entire human genome was sequenced, early descriptions of the AIDS virus, a paper on gravitational lensing by Albert Einstein, and one on spiral nebulae by astronomer Edwin Hubble.) That it was published in such a revered general science academic journal gave the study a life that no one—probably not even David Rosenhan himself—could have seen coming.

Arriving on the scene when it did, Rosenhan's "On Being Sane in Insane Places" ended up falling right in line with other, more theoretical rebukes that had been building from inside the ranks of psychiatry from people who asserted that mental illness didn't even exist. The pendulum had swung once more, this time into a third position, moving from the idea that mental illness resided in the brain as a tangible disease, like cancer, to the theory that it emerged from unresolved conflict in the mind's psyche, to the new conviction that the "illness" itself lay entirely in the eye of the beholder. Intentionally or not, Rosenhan's study ultimately built on this idea, arguing that the healthy volunteers were deemed insane *because* they were in an insane asylum, not because of any objective, external truths that psychiatry could point to for a diagnosis. Rosenhan provided the key element missing from anti-psychiatry's arguments—proof of its convictions.

The timing of the study couldn't have been more fraught for psychiatry. These were the early rumblings of psychiatry's worry years. Sobering studies cast psychiatry in a less-than-effective light. In 1971, a large-scale US/UK study showed that there was little consensus across the Pond about schizophrenia. American psychiatrists worked with a broader concept of the disorder and overwhelmingly diagnosed people with it, while British doctors were more likely to diagnose patients with manic depression, now known as bipolar disorder. Two psychiatrists on the same side of the Atlantic, studies showed, agreed on diagnosis less than 50 percent of the time—worse than blackjack odds. American psychiatrist Aaron T. Beck, who would later father the field of cognitive behavioral therapy, published two pieces on the lack of reliability in psychiatric diagnosis, concluding in his 1962 paper

that psychiatrists agreed only 54 percent of the time when diagnosing the same psychiatric patient.

Meanwhile, psychiatric hospitals closed at a rapid clip across the country. By the time California governor Ronald Reagan took office in 1967, state hospitals had released half of all their patient population. Under Reagan's leadership, California passed several acts that hastened the demise of the institutions across the state—and the rest of the country followed. Yet even as the hospitals were being closed, psychiatry's reach was spreading wide outside the asylum, like ground ivy, into Hollywood, government, education, child-rearing, politics, and big business, enjoying a sudden social cachet while turning its back on the people who needed help the most—the seriously mentally ill.

Society at large, it seemed, was ready to push back against this overextension. In the wake of his study, David Rosenhan became an academic celebrity, a media darling whose research was extensively covered in the nationwide press. It launched scores of articles, some of them outright hostile, everywhere from the *New York Times* to the *Journal of Abnormal Psychology*, as people debated the limits of psychiatry as a medical specialty. (Various Reddit pages dedicated to the study still spring up with thousands of commenters weighing in, embracing the idea that there exists a respected academic paper they can brandish to jab back at a medical specialty that, to their minds, has ignored, exploited, or abused them.) There was even a rash of pseudopatient copycats in the 1970s—including one college student at Jacksonville State Hospital who was unmasked as a faker by the staff in 1973. He was the second pseudopatient outed there in a period of six months.

The study brought Rosenhan renown as a respected expert in diagnosis, precisely because of his critique of it. (This happened despite the fact that he had spent only six months in a hospital setting early in his career, when he researched—but never treated—people with serious mental illness.) He testified in a Navy hearing about the schizophrenia diagnosis and involuntary commitment of a skipper, worked as a psychology consultant to the Veterans Administration, and became a mascot for the limitations of psychiatry at countless academic conferences. Lawyers cited Rosenhan's study as proof that a psychiatrist as an expert witness was an oxymoron—claiming that in the courtroom

such testimony was as legitimate as “flipping coins.”

When Dr. Deborah Levy introduced me to the study, I didn't yet know how the tentacles of this one almost fifty-year-old paper extended in so many wild directions that it was cited to further movements as disparate as the biocentric model of mental illness, deinstitutionalization, anti-psychiatry, and the push for mental health patient rights. Nor did I know that it would alter my perspective on something that I thought I had all figured out. Reading the study for the first time, I—like many before me—simply recognized so much of my own experience in Rosenhan's words. I had seen how doctors' labels altered the way they saw me: During my hospitalization, one psychiatrist described my plain white shirt and black leggings as “revealing,” for instance, and used it as proof that I was hypersexual, a symptom that supported her bipolar diagnosis. It's hard to ignore the judgment that comes with those kinds of labels. Yet the minute the doctors discovered my issues were neurological—after I had spent weeks living with a psychiatric diagnosis—the quality of care improved. Sympathy and understanding replaced the largely distant attitude that had defined my treatment, as if a mental illness were my fault, whereas a physical illness was something unearned, something “real.” It was the same way the psychiatrists treated the pseudopatients when the cause of their presumed distress could only be “mental.”

“It is not known why powerful impressions of personality traits, such as ‘crazy’ or ‘insane,’ arise,” Rosenhan wrote. “A broken leg is something one recovers from, but mental illness allegedly endures forever. A broken leg does not threaten the observer, but a crazy schizophrenic? There is by now a host of evidence that attitudes toward the mentally ill are characterized by fear, hostility, aloofness, suspicion, and dread. The mentally ill are society's lepers.”

I identified with the extreme loss of self that all eight pseudopatients experienced during their hospitalizations—and bristled at the blame directed at the pseudopatients, as if they didn't deserve sympathy or care. “At times, depersonalization reached such proportions that pseudopatients had the sense that they were invisible, or at least unworthy of account,” Rosenhan

wrote. I recognized their outrage over the blatant hubris of the doctors who in the face of uncertainty doubled down with an unquestionable infallibility. “Rather than acknowledge that we are just embarking on understanding, we continue to label patients ‘schizophrenic,’ ‘manic-depressive,’ and ‘insane,’ as if in those words we had captured the essence of understanding. The facts of the matter are that... we cannot distinguish insanity from sanity,” Rosenhan wrote.

In my first reading of “On Being Sane in Insane Places,” in a quiet Boston hotel room, the first of hundreds of readings to come, I saw immediately why so much of the general public had hailed it—and why psychiatry writ large despised it. I recognized the validation Rosenhan’s work gave to that father who had emailed me. I pinpointed so much of my own disappointment and frustration as a former patient myself. And I could feel, viscerally, the undercurrent of rage that travels through his paper that I feel, too, when I picture the face of my mirror image, that anonymous young woman, trapped in a psychiatric diagnosis, who would never be the same.

“You are a modern-day pseudopatient,” Dr. Levy said to me over our dinner that night, meaning that I was also misidentified as a psychiatric patient.

I took it a different way: It was a challenge, a call to learn more and understand how this study, and the dramatic questions Rosenhan raised almost fifty years ago, could help the untold others whom our health care system still leaves behind.

A RIDDLE WRAPPED IN A MYSTERY INSIDE AN ENIGMA

I had so many questions for David Rosenhan: about his experiences, about the pseudopatients, about the creation of and the challenges in implementing the study. But he had died in 2012, in those same months when I was preparing for the release of my own *Brain on Fire*. I searched eagerly for more of his work, but with the exception of one companion piece, where Rosenhan clarified some of the points made in his original study, and a short personal reference to the study in an introduction to his abnormal psychology textbook, he never again published on the topic. He had even secured a book deal, I learned, but ended up never delivering the manuscript and was later sued by the publisher for it. He had walked away from this subject that so desperately needed a champion. What had happened to silence him?

Unfortunately, I would not learn the answer easily. Google searches and basic digging led me nowhere in understanding more about the creation of “On Being Sane in Insane Places.” A news clip search revealed no further details. It seemed there was little else to find beyond the original premise—eight anonymous pseudopatients, twelve hospitals, “thud, empty, hollow.” None of the pseudopatients had gone public, their names never released. Nor had anyone revealed the identities of the hospitals they infiltrated. Rosenhan had remained tight-lipped his whole life about the identities of the hospitals (with one exception—he did reassure the superintendent of Delaware State Hospital that despite rumors, he had *not* sent pseudopatients there). He was determined to protect their privacy, he wrote, because he didn’t

serious mental illness, are actually quite common in the general population—as widespread as left-handedness, some studies say. A host of medical conditions can induce them: high fevers, of course, but also hearing loss, epilepsy, alcohol withdrawal, bereavement, and intense stress. If you do hear voices, you're joining an esteemed group that includes Socrates, Sigmund Freud, Joan of Arc, Martin Luther King Jr., and Winston Churchill.)

Guillain-Barré syndrome is an autoimmune disease that occurs when the body's immune system targets nerves, which can sometimes result in paralysis. Lee's case struck him five years before our meeting, and at one point, he could not swallow or talk. It is hard to imagine a worse fate for a man so interested in conversing with the world. After several months of treatment, hooked up to a respirator and a feeding tube, Lee recovered and the lingering effects are minor, if there are any.

Coincidentally, David Rosenhan had suffered from Guillain-Barré, too. Lee mentioned this as he pointed out the office down the hall where Rosenhan had worked for more than thirty years. That two people who shared the same floor of a small office building had had the same rare autoimmune disease shocked one doctor with whom I shared this information—it's a one-in-a-billion chance, the doctor said. But it was true: I would later confirm this coincidence with Rosenhan's family and friends. It was the first of many small, improbable details I would encounter in my investigation.

Before my visit, Lee had set aside a stack of books that had once belonged to Rosenhan and that Lee believed were key to his thinking: *The Myth of Mental Illness* by Thomas Szasz, *Self and Others* by R. D. Laing, and *Asylums* by Erving Goffman—all works associated with the anti-psychiatry movement.

As I thumbed through Rosenhan's books, Lee told me the origin story of their friendship. They had met in the early 1970s when Rosenhan joined Stanford's psychology faculty after leaving Swarthmore College. Stanford in those days was home to an all-star roster of psychologists, including Philip Zimbardo, who led the much-publicized Stanford Prison Experiment in 1971. The observational study, which recently spawned a movie, purportedly simulated prison life in the basement of the university's Jordan Hall with volunteers playing the parts of fake guards and fake

prisoners. After a few days, the guards, drunk on their own power, abused the prisoners, who withdrew and grew resigned to their fate. Zimbardo's study was published in 1973, not long after Rosenhan's. The Stanford Prison Experiment made Zimbardo a legend the same way "On Being Sane in Insane Places" did for Rosenhan.

Lee and I had been chatting for a few minutes when he casually reached up and removed a box stuffed with papers from the top of his filing cabinet. He fingered through files, stopping at a fat folder bursting with pages.

I blinked. Realizing what it contained, I couldn't believe my luck—if I was right, this treasure trove would be almost as good as being able to interview Rosenhan himself. Pages peeked out from a folder titled ON BEING SANE and another marked PSEUDOPATIENTS. Papers stuck out in various directions. The files were organized, or rather disorganized, according to how Rosenhan left them—once I started pawing through it I quickly realized that the mess revealed more about his mind than anything sanitized by an archivist. There was something voyeuristic, even indecent, about the digging, but, for better or worse, my years working in a tabloid newsroom weaned me off any shame about going through people's dirty laundry.

Sometimes the contents corresponded to the description on the folders; often they did not. You'd open up a folder on, say, Rosenhan's work about altruism in children and you'd find a bill of sale for his Mercedes. There were drafts of "On Being Sane in Insane Places," which Rosenhan had cut out into sections and pasted back together like an elaborate puzzle, and dozens of pages of handwritten diary entries from his time inside the hospital. A folder marked CRITICISM held brutal comments from his peers: "pseudoscience presented as science," "unfounded," "entirely unwarranted." If this folder was any indication, Rosenhan clearly had pissed off psychiatrists. And he seemed proud enough of it to keep the evidence.

I came to a stack of paper held together by a thick but weathered rubber band. The first page read: