

# PART ONE

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*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

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## 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,<sup>1</sup> 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,

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1. Serious mental illness is defined by the National Institute of Mental Health to be “mental, behavioral or emotional disorder . . . resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities.”

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 ever-present 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.”