ANNALS OF MENTAL HEALTH

GOD KNOWS WHERE I AM

What should happen when patients reject their diagnosis?

BY RACHEL AVIV

On October 5, 2007, two days after being released from New Hampshire Hospital, in Concord, Linda Bishop discarded all her belongings except for mascara, tweezers, and a pen. For nearly a year, she had complained about the restrictions of the psychiatric unit, but her only plan for her release was to remain invisible. She spent two nights in a field she called Hoboville, where homeless people slept, and then began wandering around Concord, avoiding the main streets. Wary of spies, she sat through the underbrush behind buildings, walked through gullies beside the roads, and, when she needed to rest, cuddled in the bushes. Her life was saved along the way, she later wrote, by two workers and an owl.

A tall, athletic fifty-one-year-old with blue eyes and a bachelor’s degree in art history from the University of New Hampshire, Linda had been admitted to the hospital in late October, 2006, after having been found incompetent to stand trial for a series of offenses. She spent most of her eleven months there reading, writing, and crocheting. She refused all psychiatric medication, because she believed her diagnosis (bipolar disorder with psychosis) was a mistake. Each time she met a new psychiatrist, she declared her lack of respect for the profession. Only when conversations moved away from her mental illness, a term she generally placed in quotation marks, was she cheerful and engaged. Her medical records consistently note the same traits: “extremely bright,” “very pleasant,” “denies completely that she has an illness.” In the weeks leading up to her discharge, her doctors urged her to make arrangements for housing and follow-up care, but Linda refused, saying, “God will provide.”

During a rainstorm on her fourth day out of the hospital, Linda broke into a vacant farmhouse for sale on Mountain Road, a scenic residential street. The three-story home overlooked a brook and an apple orchard, and a few rooms were still sparsely furnished. Linda intended to stay only a few nights, but she began to worry that her dirty clothes would attract attention if she walked back to town. “I look terrible . . . like a vagrant,” she wrote in a black leather pocket notebook that the previous tenants had left behind. Linda had led a nomadic existence ever since she had abandoned her sleeping-thirteen-year-old daughter, in 1999, leaving a note saying that she was going to meet the governor. She drifted between homeless shelters, hospitals, and jail. She wrote in the journal that she wasn’t ready to “make my presence known—and just start the whole mess again—to prove what—that I’m all right! Have done that too many times.” Two days after breaking into the house, she decided to make the place her temporary home. She would subsist on apples while “awaiting further instructions” from God.

Linda settled into a routine. In the morning, when the sun poured through the living-room window, warming the end of the couch, she read college textbooks she found in the attic. The former tenant appeared to have dropped out of school in 1969 (“but his creative writing is very good,” she noted), and she began embarking on the education he had abandoned. She began with Joseph Conrad and moved on to biology (“chloroplasts, lysosomes, mitochondria + cell division!”) and “Great Issues in Western Civilization.” When she had enough energy, she did her “chores.” She combed her graying brown hair—first with a small rake, and, when that proved too cumbersome, with a fork—and tidied the house, in case potential buyers came for a viewing. There was no electricity or water, but, after dusk, she rinsed her underwear in the brook, collected water with a sieve, and picked apples.

After the first week, she estimated that she had lost ten pounds. When she looked in the mirror, she was startled by how drawn her face had become. Yet after enduring so many irritations in her hospital unit—patients who wouldn’t stop talking; or who touched her, or sat in her favorite chair, or made noise in the middle of the night—she didn’t mind having time alone. From her windows, she enjoyed watching purple finches, tufted titmice, chickadees, and “Mr. and Mrs. Cardinal.” She wished she had binoculars. A neighbor came to mow the lawn and pull the weeds.

“He has no idea I’m here!” Linda wrote, as she watched him from an upstairs window.

The threat that Linda was hiding from was a shifty one—she alluded to conspiracies involving her older sister, the government, and Satan’s workers—but she also wondered if anyone was even looking for her. She kept retracing the series of events that had led her to this house. She knew it didn’t “make sense to be barely existing”—she got light-headed just walking up the stairs—but she felt that the situation must have been willed by the Lord. By the end of October, she had a stash of three hundred apples. She worried about the coming winter as she watched trees lose their leaves, milkweed seeds blow in the wind “like it’s snowing,” and geese migrate south. Still, she could find “no signs or clues that I should be doing anything different.”

Throughout Linda’s stay at New Hampshire Hospital, her doctors routinely noted that she lacked “insight,” a term that has a troubled legacy in psychiatry. Studies have shown that nearly half of people given a diagnosis of psychotic illness, such as schizophrenia or bipolar disorder, say that they are not mentally ill—naturally, they also tend to resist treatment. The psychiatrist Au-
brey Lewis defined insight in 1934 in the *British Journal of Medical Psychology* as the “correct attitude to a morbid change in oneself.” But the definition was so ambiguous that his paper was ignored for over fifty years. Psychiatrists were reluctant to move away from objective, observable phenomena and to examine the private ways that people make sense of the experience of losing their minds. Today, insight is assessed every time a patient enters a psychiatric hospital, through the Mental Status Examination, but this form of awareness is still poorly understood.

Patients are considered insightful when they can reinterpret unusual occurrences—growing angel’s wings, feeling as if their organs have been removed, decoding political messages in street signs—as psychiatric symptoms. In the absence of any clear neurological marker of psychosis, the field revolves around a paradox: an early sign of sanity is the ability to recognize that you’ve been insane. (A “correct attitude,” for most Western psychiatrist, would exclude interpretations featuring spirits, demons, or kartric disharmony.)

Getting patients to acknowledge their own disorders also has become an ethical imperative. Implicit in the doctrine of informed consent is the notion that before agreeing to take medication patients should be aware of the nature and course of their own illnesses. In balancing rights against needs, doctors, psychiatry is stuck in a kind of moral impasse. It is the only field in which refusal of treatment is commonly viewed as a manifestation of illness rather than as an authentic wish. According to Linda’s treatment review, her most perplexing behavior was her “continuing denial of the legitimacy of her ‘patienthood.’”

When psychoanalytic theories were dominant, patients who claimed they were sane were thought to be protecting themselves from a truth too shattering to bear. In more recent years, the problem has been reframed as a cognitive deficit intrinsic to the disease. “It has nothing to do with willfulness—you just don’t have the capacity to know,” Xavier Amador, an adjunct professor of psychology at Columbia University’s Teachers College, said. Amador is the author of the most widely used test for measuring insight, the Scale to Assess Unawareness of Mental Disorder, which asks patients why they think their judgments or perceptions have changed. Although researchers haven’t uncovered distinct neurological anomalies linked to lack of insight, Amador and other scholars have adopted the term “anosognosia,” which more typically describes patients with brain damage who lose the use of limbs or senses yet cannot acknowledge the existence of their new disabilities.

Those who go blind because of lesions in their visual cortex, for instance, insist that they can still see, and tell fanciful stories to explain why they are walking into furniture.

Anosognosia was introduced as a synonym for “poor insight” in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders, but the concept remains slippery, since the phenomenon it describes is essentially social: the extent to which a patient agrees with her doctor’s interpretation. For Linda, the validity of her diagnosis was the subject of nearly all her encounters with her psychiatrists, whose attempts to teach her that parts of her personality could be “constituted as a mental illness,” as she described it, only alienated her. She wrote to a friend that she was using her hospital stay as an opportunity “merely to prove that I don’t have a mental illness (and never did).”

Linda had always been fond of farmers. She grew up on Long Island and took pride in her family’s sprawling vegetable garden. “My childhood was a good one, with loving and supportive parents who believed in doing things as a family,” she wrote in an application to an assisted-housing program. She had a large circle of friends and excelled in school with little effort. “She was bubbly and exuded competence,” an old friend, Holliday Kane Rayfield, who is now a psychiatrist, said. Linda’s family thought she would become a professor, but she never settled on a professional career. Kathleen White, her closest friend from college, said that her “dream was to find a guy with a sense of humor, have kids, and live on a farm.”

Linda got married in 1985, and gave birth to her daughter, Caitlin, five months later. But she complained about her husband’s temper, and after their brief marriage ended she struggled to support Caitlin on her own. She worked long hours at a Chinese restaurant in Rochester, New Hampshire, and on her days off she and Caitlin visited museums in Boston or went on camping trips or took aimless drives through the state. Caitlin, now a twenty-five-year-old photo technician at Walmart, told me, “We were each other’s world.” It wasn’t until her mother quit her waitressing job in order to evade the “Chinese Mafia” that Caitlin, who was in seventh grade, began to doubt her mother’s judgment.

In 1999, in a purple Dodge Dart, the two fled the state, heading toward Canada. Caitlin, too, was terrified of being captured. “I figured I was collateral damage,” she said. Linda called friends on the way but lied about her location, because she suspected that she was talking to spies. While her mother used pay phones at gas stations, Caitlin waited in the car. “At some point, I just thought to myself, I know better than this,” she said.

When they returned, a little more than a week later, after Linda’s fears had subsided, Linda’s sister, Joan Bishop, and their parents tried unsuccessfully to persuade Linda to see a doctor. Soon, she disappeared again. She went to Concord, the state capital, to inform authorities that the government had been behind John F. Kennedy, Jr.’s plane crash, and then wandered alone through the state for several days, feeling as if she had “ingested some sort of poison or drug without knowing it.” Caitlin moved in with her paternal grandmother and stayed there even when Linda came home. Linda finally checked into a hospital in Dover, New Hampshire, where she was given a diagnosis of schizoaffective disorder, and began taking Zyprexa, an antipsychotic, and lithium, a mood stabilizer. (Her diagnosis shifted between bipolar and schizoaffective—a mixture of schizophrenia and a mood disorder—depending on the doctor.) Psychotic disorders typically begin in
only adulthood, but it is not uncommon for them to develop later in life, particularly after periods of stress or isolation. Linda sobbed for the first few days, and talked about how betrayed she felt by those who were scheming against her. By the fourth day, though, her psychiatrist wrote, “She now has insight into the fact that these are paranoid delusions, and a part of her is able to say that maybe some of these things didn’t happen, perhaps some of the people she felt were plotting against her really weren’t.” Two days later, she was released.

It was the beginning of a persistent and common cycle. With each hospitalization, Linda was educated about her illness and the need for medication. This is the standard approach, for increasing insight, but it does not account for the fact that people’s beliefs, even those which are wildly false, shape their identities. If a person goes from being a political martyr to a mental patient in just a few days—the sign of a successful hospital stay, by most standards—her life may begin to feel banal and useless. Insight is correlated with fewer hospital readmissions, better performance at work, and more social contacts, but it is also linked with lower self-esteem and depression. People recovering from psychotic episodes rarely receive extensive talk therapy, because insurance companies place strict limits on the number of sessions allowed and because for years, psychiatrists have assumed that psychotic patients are unable to reflect meaningfully on their lives. (Eugen Bleuler, the psychiatrist who coined the term “schizophrenia,” said that after years of talking to his patients, he found them stranger than the birds in his garden.)

With medication as her only form of treatment, Linda was unable to modify her self-image to accommodate the facts of her illness. When psychotic, she saw herself as the heroine in a tale of terrible injustice, a role that gave her confidence and purpose. After the World Trade Center attacks, in 2001, she moved to New York City, because she felt she had been called to offer her help. A December, 2001, article in the New York Post, “Homeless Angel, a Blessing at Ground Zero,” described how Linda patrolled the perimeter of the site, waving an American flag, greeting visitors, and giving impromptu tours. “Angels come to earth in disguises—some come as paupers,” a construction worker was quoted as saying. A man identified as a 9/11 victim said that “God rested on her shoulder.” Linda thanked workers at the site for their efforts and talked to tourists about what they were witnessing. “I try to help people understand the enormity,” she told the reporter. She dubbed herself the head of Hell’s Chamber of Commerce.

For the next few years, Linda wandered: she lived on the streets, in homeless shelters, and in her sister’s house, on the condition that she take medication. Joan, who works as the director of education for the New Hampshire Supreme Court, has the same warm, joyful manner as her sister, and the two spent much of their free time together, though Linda’s goal was to find her own home. In 2003, she entered a supported-housing program in Manchester, New Hampshire, and told her caseworker that she wanted to “live like an adult again.” She was upset that her illness had alienated her daughter and friends. Joan told me that “Linda would talk analytically about how it had felt to be delusional. It wasn’t a matter of imagining. It wasn’t as if she felt she was being chased by government agents. In her mind, they were as real as I am right now.”

In the summer of 2004, Caitlin, by then a senior in high school, decided to move back in with her mother for the first time in five years. Their new apartment, in Rochester, New Hampshire, became the preferred hangout spot for her friends. “She was the cool mom,” Jessica Jamouska, a close friend of Caitlin’s, said. “She had stopped talking about the government, except maybe if there was an election. And the only reason she quoted the Bible is if we were having intellectual debates about, you know, whether it’s a book of morals or not.”

Linda enjoyed cooking large meals for Caitlin’s friends, but over time the stories she told at the dinner table became harder to follow. “At first, we just thought, O.K., it’s normal to have some fantasies and dreams,” Jessica said. “She would talk a lot about some dude she loved who was going to make everything all right, and we weren’t even sure he existed.”

Caitlin and Joan urged Linda to take her medication, but she said that she felt perfectly fine and complained that the drugs made her lethargic and caused her to gain weight. (Linda’s parents, who had encouraged her to follow her doctors’ advice, had died, both of them from can-
cer, in 2003 and 2004.) Caitlin and two of her friends finally decided to make an audiotape of Linda ranting. "We wanted to have proof, to say, look, this is objectively crazy, and someone needs to help her," Caitlin said. They recorded her talking about how children should be armed with AK-47s, and called the police, but Caitlin said that their complaint was never taken seriously. In February, 2005, Linda's car flipped on its side on Rochester's main street. When the police arrived, they smelled alcohol on her breath. She said that she had purposely caused the accident, to prove "that police officers are illegal."

Although it was a relatively minor offense (her alcohol level was below the legal threshold), Linda refused to pay the five-hundred-dollar bail, so she was sent to the Strafford County House of Corrections, in March. (Nationally, a quarter of jail inmates meet the criteria for a psychotic disorder.) After her first arrest, Linda threw a cup of urine at a corrections officer and struck a man with a broomstick. Joan wrote to the police department's prosecuting attorney, explaining that before her illness Linda had never been "violent or aggressive towards anyone or anything." She said that the family hadn't been able to get Linda into psychiatric treatment, and asked the attorney to help. Joan's request led to competency evaluations, and, as Linda waited in jail for the results, she moved even farther away from the life she had led before her illness. She considered herself a "people person"—she made Christmas cards for other inmates out of lunch bags and magazine ads, scaled with grape jelly—but she found herself isolated from all the people with whom she had once been close. She wrote Caitlin long letters with tips about what to wear, how to get a job, shop for bargains, lose weight, make apple pie, and avoid the presence of people who belong in Hell, but Caitlin stopped responding.

After a year and a half in jail, Linda was deemed incompetent to stand trial and was transferred to New Hampshire Hospital for a commitment term of up to three years. She was humiliated by the idea of anyone evaluating her competence and wrote to Caitlin, "My constitutional rights have been ignored, trampled on and violated due to your Aunt Joan."

New Hampshire Hospital was established in 1842, as a kind of utopian community, a refuge from the disorder of the outside world. The hospital's early leaders tried to help patients regain their common sense—in the year, more than a quarter of armed patients suffered from an "overabundance in religious thoughts," with several claiming to be prophets—by immersing them in a model society. The hospital was situated on a hundred seventy acres, and patients lived in stately, red-brick Colonial buildings with steeples and a tiered white porch, surrounded by trees. They farmed, gardened, and cooked together; there was a golf course, an orchestra, a monthly newspaper, dances, and boating on the hospital's pond. In 1866, the hospital superintendent described psychosis as a "waking dream, which, if not broken in upon, works mischief to the brain," and wrote that the goal of treatment was to "interfere with this world of self—scatter its creations and fancies and people it with objects and thoughts foreign to its own."

As the patient population expanded, though, the hospital couldn't maintain its early idealism. Psychiatrists no longer had time for the bestial form of care known as "moral treatment." As of 1896, the hospital had sterilized a hundred and fifty-five patients, and later it began experimenting with newfangled remedies, like electroconvulsive therapy and insulin-induced comas; the shock of such procedures, it was thought, might clear patients' minds. By the nineteen-fifties, the hospital's population had swelled to twenty-seven hundred patients, and doctors were less concerned with creating a sense of community than with maintaining security. Patients spent so many years in the hospital that they no longer knew how to leave it. (The institution has two graveyards for people who died in its care.)

The hospital's crowded wards resembled those studied in Erving Goffman's 1961 book, "Asylums," which showed how, through years of institutional life, people lost their identities and learned to be perfect mental patients—dull, unmotivated, and helpless.

The idea that mental illnesses were exacerbated, even caused, by the measures designed to treat them was elaborated by many scholars throughout the sixties. Thomas Szasz, a psychiatrist and prolific author, described mental illness as a "myth," a "meta
The psychiatrist R. D. Laing called it "perfectly rational adjustment to an insane world." In 1963, President Kennedy (whose sister Rosemary had received a lobotomy which left her unable to speak) passed the Community Mental Health Centers Act, which called for psychiatric asylums to be replaced by a more humane network of behavioral health centers and halfway homes. His "bold new approach," as he called it, was plausible because of the recent development of antipsychotic drugs, which seemed to promise a quick cure. In the years that followed, civil-rights lawyers and activists won a series of court cases that made it increasingly difficult for patients to be treated without their consent. In 1975, the Supreme Court ruled that the state may not "fence in the harmless mentally ill." Four years later, in Rogers v. Okin, a federal district court decided that involuntary medication was unconstitutional, a form of "mind-control." The court maintained that "the right to produce a thought—or refuse to do so—is as important as the right protected in Roe v. Wade to give birth or abort."

Deinstitutionalization was a nationwide social experiment that didn't go as planned. Overgrown hospitals were shut down or emptied, but many fewer community centers were opened than had been proposed. Resources steadily declined; in just the past three years, $2.2 billion has been cut from state mental-health budgets. "Wishing that mental illness would not exist has led policymakers to shape a health-care system as if it did not exist," Paul Appelbaum said in his 2002 inaugural address as president of the American Psychiatric Association. Today, there are three times as many mentally ill people in jails as in hospitals. Others end up on the streets. A paper in the American Journal of Psychiatry, which examined the records of patients in San Diego's public mental-health system, found that one in five individuals with a diagnosis of schizophrenia is homeless in a given year.

New Hampshire Hospital, which now has only a hundred and fifty-eight beds, admits people who have been sent from jail or who pose a danger to themselves or others. Often, people arrive at the emergency room, with concerned relatives and friends, but they are turned away because they are not an imminent threat. "Clinically, it's a shame," Alexander de Nesnera, the hospital's associate medical director, told me. "These are people who may be making choices they would never have made when they were healthy. But then there's the civil-libertarian argument: Who are we to say that they don't have the right to change their opinions?"

Freedom often ends up looking a lot like abandonment. Tanya Marie Luhmann, a Stanford anthropologist, told me that there is something deeply American about the force of our insistence that you should be able to ride it out on your own. Luhmann has followed mentally ill women in Chicago through what is known as the "institutional circuit"—the shelters, halfway homes, emergency rooms, and jails that have taken the place of mental asylums. Many of the women refused assisted housing, because to gain eligibility they had to identify themselves as mentally ill. "They would not formulate the sentence that psychiatrists call 'insight,'" Luhmann said. "I have a mental illness, these are my symptoms, and I know they are not real."—the whole biomedical model. To ask for this kind of help is to be aware that you cannot trust what you know."

Linda readily acknowledged that her life had gone away, but she insisted that her diminished circumstances had nothing to do with being "crazy." After reading a booklet on domestic violence, she concluded that her sister was trying to abuse her by convincing others that she was ill and stealing her inheritance. "This will make a great book—a N.Y. Times best seller," she wrote to a friend from the hospital.

Three months into Linda's stay, the hospital filed a petition to make her sister, Joan, her legal guardian, with the authority to force her to take medication. The hospital had to prove beyond a reasonable doubt—the same threshold used in criminal trials—that Linda was incapable of making her own decisions. At the hearing, Linda told the judge that her only problem was that she was "permanently pissed off." "I have a huge amount of medical knowledge," she said. She pointed out that she took daily vitamins, wore anti-embolism stockings, had recently agreed to a mammogram, passed a first-aid course when she was sixteen, and had an uncle who was a podiatrist. To the charge that she was manic, she
said, "I've always been like this. Okay? I'm a waitress, I have a lot of energy." The judge found that the evidence of Linda's incapacity—her refusal to accept why she was a patient—did not meet the burden of proof. Linda had become a person that both her sister and her daughter hardly recognized, but the court cannot deprive an individual of her legal rights just because her personality has changed. "She wasn't screaming, she wasn't talking to the ceiling," Joan said.

After the guardianship hearing, which Linda's psychiatrists viewed as their one chance to medicate her, they began talking about her release, though hospital staff continued to express concern about Linda's belief in "the 'plot.'" The psychiatrist who gave a second opinion on her discharge predicted that Linda would "probably get into further alterations with the police" and end up back at the hospital; then there would be more evidence to apply again for a legal guardian. A third of patients discharged from New Hampshire Hospital are readmitted. "Her pattern," he wrote, "is to attract attention to the police before situations become sufficiently dangerous." He seemed to feel that only law-enforcement officials had the power to lead her to treatment.

Linda had spent time away from the hospital on her daily "community passes"—she usually sat in a square in Concord, crocheting and people-watching—but she always returned before dinner was served. She was an active participant in support groups called Inner Strength, Loss & Recovery, and Lifestyle Choices, but she avoided meeting that had a therapy component. According to worksheets she filled out at one group, "freedom" was her only long-term goal. Her short-term goals included "get clothes," "get out," and "laugh more."

A hospital assistant who checked on patients every fifteen minutes to see "if they're breathing" developed a friendship with Linda and encouraged her to think seriously about what she would do after her discharge. But Linda cut off their conversations. "I remember her walking down the hall and she turned around and she said, 'You're putting your values on my life,'" the assistant later explained. "That was my moment. That was, like, I have to back off."

Linda's only plan for supporting herself was to sell some mittens and doilies she had crocheted. Although she had complained of the indignity of being homeless, she didn't authorize the hospital to share her records with a free transitional-housing service, because when she reviewed the paperwork she saw her diagnosis. "If refuse to sign anything that says I am mentally ill," she told her social worker. Instead, she left the hospital with only pocket change, no access to a bank account, and a single person aware of where she was going.

Because of patient-privacy laws, Linda's doctors never informed Joan or Caitlin that she had been released, and they could not tell them about her condition during her hospitalization, either. Joan sent money and dropped off clothes, but Linda would not see her, and Joan began to feel as though she were only getting in the way. In 2006, she joined the National Alliance of Mental Illness, an organization with twelve hundred chapters created by family members (known as "NAMI mommies") who felt excluded from the medical decisions made by their loved ones. When the organization was founded in 1979, psychosis was not seen as a reaction to a dysfunctional family. According to a prominent theory of the time, the root of schizophrenia was a "schizophrenogenic mother," incapable of communicating her love.
her mother fainting next to this beaten tree.
Nighthawks works a bit thread through the evening.
The calliope makes the air timny.
The strongman presses six hundred pounds,
his muscles flexed for the woman
whose T-shirt says, "These guns are loaded."
But one minute later he's on the ground,
a petite bystander giving him mouth-to-mouth.
A cop blows his shiny whistle,
trying to clear a path for the paramedics.
Teenagers slurp root-beer floats
& munch corn dogs, after they've leaned
into each other's arms in the flipped-over,
high-spinning ride & have fallen in love
for the second time in three weeks.

—Yasuf Komanyaka

with schizophrenia and bipolar do not
take their medications." A Treatment
Advocacy Center briefing paper on ano
sognosia quotes a quotation from a Jac
obean play, "The Honest Whore," by
Thomas Dekker. "That proves you mad,
because you know it not."

Yet the notion that denying an illness
is proof of its existence is a dangerous
one, since there are many valid reasons
that people choose to refuse treatment,
including the stigma of having a mental
illness and the disabling side effects of
medication. Elyn Saks, a professor of
law, psychology, psychiatry, and the behav
ioral sciences at the University of
Southern California, who has schizo
phrenia, said, "Alleviating suffering is
not a legitimate reason for 'taking away
people's rights.'" When Saks was a law
student at Yale, she was restrained and
medicated against her wishes; she calls it
one of the most degrading experiences
of her life. She argues for a greater use
of advance directives, which function as
psychiatry's version of the living will. In
the past two decades, twenty-six states
have passed laws that allow people to
specify what kind of medical care they
wish to receive if they lose their gras
p on reality. Some directives include a
Ulysses contract," just as Ulysses instru
cted that he be bound to the mast of
his ship so that he would not be lured
by the Sirens, some people insist in ad
vance that they be medicated or hospi
talized even as they beg to be released.

At the other extreme, people use direc
tives to reject any future treatment at all.
In her book "Refusing Care," Saks
calls the method "self-paternalism," and
argues that there are few other scenarios
in which psychiatrists should forcibly
impose treatment that intrudes on the
privacy of people's own minds. A widely
cited justification for compulsory treat
ment is the "thank-you theory," which
assumes that patients will retroactively
agree that the intervention was in their
best interests. But even a handful of pa
tients who have been involuntarily hos
terized subsequently say that they
needed the treatment. "We should not
be in the business of choosing selves,"
Saks writes. "It's impossible to deter
mine whether a mental illness has altered
someone's preferences, or whether that
person has simply changed.

The concept of anosognosia is held
in disdain by what is known as the "c/sx
movement," composed of consumers,
survivors, and ex-patients, who argue that
biological explanations for mental disor
ders have been unilaterally embraced.
They maintain that one of the reasons so
many patients lack "insight" is that they
are asked to accept a model of illness that
doesn't resonate with their own experi
ences. Although psychotic disorders have
a strong genetic component, popular
opinion has swung so far from the logic
of the psychoanalytic era, when mothers
were blamed for their children's illnesses,
that psychosis is often described as if it
were inevitable and contextless—a stroke
of bad luck. Daniel Fisher, a psychiatrist
with a doctorate in biochemistry, who is
the executive director of the National
Empowerment Center, run by former
patients, said that "if you accept the idea
that you have this random brain disease,
then suddenly your sense of self, your
ability to make judgments, and the most
fundamental elements of your personal
ity are biologically determined, and this
just leads to a sense of meaninglessness
and hopelessness."

When Linda arrived at the house
on Mountain Road, her mood oscillated
during despair and exhilara
tion at her sudden freedom. For the
first time in years, she saw the poten
tial to start her life anew, on her own
terms. She finally had her own home,
a plot of land, and no one telling her
what to do.

During her illness, the person with
whom Linda felt closest was a man
named Steve Shadulis, whom she con
sidered the love of her life. Steve met
Linda a few times in 1996—"she was a
nice waitress who seemed lonely," he
told me—but, beyond talking the jive in 2005
and asking to block Linda's letters, he'd
had no contact since. He was told that
inmates could write to whomever they
pleased.) While in jail, Linda told Cait
lin: to design bridesmaid dresses for her
and her friends, because she and Steve
were getting married. "He wants a big
church wedding," she wrote, "which is
fine with me.

Linda had spoken of Steve in raptu
ous tones at the beginning of her illness,
but she was self-conscious enough then
to recognize her fantasy. She even wrote
a letter to a friend explaining that the
process I am going through is not about
a relationship with Steve, it is about
my relationship with myself." But by
the time Linda got to New Hamp
shire Hospital, she considered herself
Steve's wife. Now, at the house on
Mountain Road, she imagined their domestic
routine—they would eat homemade dinners and watch the sunset, holding hands, after “finishing with the needs of business of the day”—and searched the attic for clothes so she would look attractive if Steve arrived. All she could find was a hat.

A plan took shape. Steve would rescue her sometime near Advent, the beginning of the new liturgical year. After gazing at the sky and seeing a cluster of clouds forming the number 4, Linda determined that he’d arrive by December 4th. Using long division and multiplication tables that fill the margins of the last page of her notebook, she calculated that she could survive the “Attic + Apples chapter of this book” if she limited herself to twelve apples per day.

Having spent two years in institutional settings with precisely timed meals and activities, Linda had got into the habit of checking her watch, and she began many of her diary entries, up to four a day, by noting the time. The “high point” of each day was the moment when she crossed off another date on her makeshift calendar, which she usually did around four o’clock. She discovered new books in the attic and under a couch—“What the Bible Is All About,” “Medical Self-Help Training,” Webster’s New World Dictionary, “Can America Survive?”—but the days dragged. It was difficult to do anything but think about food. She composed long lists of groceries, both a budget list and a “wish list” (vermicelli, pepperoni, V-8, squid), and twenty-five vegetables she intended to grow. She imagined how she’d remodel the kitchen so that she could build a smokehouse like the one in “Little House in the Big Woods.”

“What the Bible Is All About” was a source of inspiration, and she transcribed a number of verses about the glory of following God’s path. Psychosis commonly coincides with religious reveries, and the longer Linda was of her medication the more everyday occurrences seemed to be laced with hidden connections and symbols. Faith in the Lord’s plan for her became essential as the days shortened and the temperature dropped. Her neck ached because she spent about sixteen hours a day curled up under blankets on a mattress, in order to stay warm. So much hair fell out each time she combmed it that she realized she might need a temporary wig. But it was “nothing a little fresh air, sunshine, exercise, good food + love won’t remedy in a short period of time.”

Linda looked out for Steve’s white Chevy truck, but by the beginning of December her conviction began to waver. “So maybe the fact that I haven’t seen him is a good sign?” she wrote. “I just hope God does want us to be together—everything seems to assure that—but who knows how it all fits. Certainly my death at this point does not seem beneficial to God’s plans as perceived by me.”

On December 4th, the sight of Christmas lights on a house down the road made her break into tears. She and Caitlin had always enjoyed decorating their tree to excess, and she hadn’t seen a lit-up house in two years. By afternoon, Steve still hadn’t arrived. Linda was so desperate that she contemplated visiting a neighbor’s house and calling a domestic-violence center. But she worried that Satan’s workers could be waiting for her. “Dear God,” she wrote, “Please save me. I’m trying but don’t know what to do. Amen.”

The next day, she ate the last of her apples.

On the morning of December 5th, Linda started a new journal, a spiral-bound composition notebook with full-sized pages that made it easier for her to write while sitting in the “hot seat,” a chair she had placed over the only working heating vent in the house. Although the previous night had been “tough,” she felt calm and hopeful as she watched the sun rise. The concerns of everyday living briefly receded, and the story she was writing, a tale of love and redemption, became her reality again. “I love my husband so much—and he has done so much to keep me going and...”
"Give me hope," she wrote. "I can't leave this up to the gods."

She tried reflecting on the positive aspects of her situation—she no longer had to deal with the "babble or whining" or lies of the hospital—but there was still the problem of her "meal plan." The following day, she wrote, "Facing death by starvation was horrifying and traumatic—and took quite awhile to adjust and consider the whole situation rationally and spiritually." She decided that she had to leave the house. "Before I die, I'll try to change (my location) I always knew—but usually there was an exterior human impetus. However, if I stay here—I will die." She planned to hitchhike to the home of some elderly couple, friends of her parents, who lived a few miles away. She would get food, take a shower, and do laundry. From there, she would head to the supported-housing program in Manchester, where she had lived in 2003; the year that her sister thought she had finally recovered.

But walking to the kitchen made her so dizzy that her vision failed. She couldn't imagine how she would get to the road, which was about twenty yards away. She had never doubted her decision to live in the house, and it didn't seem right to abandon faith at such a late stage. "So I'll wait," she wrote, "and continue to pray since God knows where I am."

Linda had never intended to "be clinging to life like some idiot," she wrote, but there was also something willful about her withdrawal from human contact. She knew that if she entered society people would be "pointing me as disabled." After praying one night, she even questioned whether God "has given me a good brain to figure out what to do." She seemed to accept the premises of two conflicting realities: a phenomenon known as "double bookkeeping," in which psychotic patients who are able to distinguish reality from fantasy can go on living and believing in both. The patient convinced that he is Christ will abide by hospital curfew and take out the trash. People rarely get insight in an absolute sense. Solitude allowed Linda's delusions to flourish, and at times she seemed aware of this; she kept away from anyone who could challenge her interpretation of the world.

With the winter weather, Linda's daily chores required less movement. She snacked on the porch or scooped up bowls of soup and melted them on the hot register, which took about an hour. The task of "harvesting" water was the central activity of her days. She took care to move slowly, since she had already fainted once and had fallen in the kitchen. She conserved energy by lying still on the living-room floor near the register, absorbing its "radiant warmth." To keep her mind active, she forced herself to read the dictionary, but she never got past the letter "K."

On Christmas, Linda reached out the window to get snow for what she predicted would be the last time. Most of the entries that follow are only a few words long, written in faint, uneven letters, because she wrote lying down. Her final note was on January 13, 2008, and it contains nothing more than the day of the week, Sunday. It had been thirty-nine days since she ate her last apple.

On the first page of the notebook, Linda left a note addressed to "whomever finds my body," in which she explained that her death would be the result of domestic violence: "I talked with and wrote to many people in position of authority about this—but no one helped me." She asked to be buried in the cemetery of the town where she had lived when Caitlin was a child and ended the letter with a request, underlined in bold strokes, "Jesus take me home."

Joan Bishop discovered that her sister had been discharged from the hospital when a Christmas card she sent to Linda was returned in the mail three months later. The envelope contained a slip of paper with a new address listed for Linda, but the location didn't exist. After all her attempts to get her sister treatment, Joan was furious that the hospital had "let her walk off the face of the earth." "I worked for the justice system, I believe in the justice system," she said. "I still don't understand how you have the right to rot away."

Joan and Caitlin sued the hospital for failing to properly plan Linda's discharge, relying on the police as her only safety net. "Ask the daughter," Caitlin said. "I could have told them that every time the structure is gone she goes right down the tubes." The attorneys representing the hospital argued that Linda's doctors had a legal duty to allow her the right to live in the least restrictive setting that her disability allowed. They ended up arguing the case that Linda had not been making all along: she wasn't that ill. In the written mediation statement, the attorneys maintained that Linda was making a reasoned decision to pursue an alternative lifestyle. As evidence, they pointed to vivid passages in the journal found at the house after her death: the pleasure she took in identifying birds and commenting on the shapes of clouds, the fact that she realized her unkeep appearance might bring her to the attention of authorities who would hospitalize her again.

Caitlin read the journal and was hurt that it appeared in it only once, when Linda wrote about a dream in which Caitlin was calling out for her. "I'll never understand that, because my mom was always thinking of me," she told me. Although the suit was settled in mediation for a small sum, Caitlin seemed ambivalent about whether she could blame the doctors. She held on to an image of a mother who was obstinate and purposeful, rather than overwhelmed by an illness. "The woman who wrote that journal—that was not my mother," she said.

Linda's body was found in early May, when a man interested in buying the house on Mountain Road peered through a window. He contacted the police, who called the owners of the house, a brother and sister who had inherited the property from their parents. One of the owners had checked on the house around Christmas, but she never went inside, because the driveway was covered in snow and there were no footprints. When Caitlin learned of her mother's death, she responded as if she had been waiting for the news for a long time. "My mom made a choice—she could have walked out of that house," she said. "But she wouldn't give up her freedom. She could never let go of that person she always wanted to be."

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A conversation with Rachel Aviv