ONE

It's Safe Here

For the entire period of time between 21 October 1723—when the prior and nuncio agree to continue keeping Hu shut up in Charenton as a charity patient—until 9 August 1725, a period of 658 days, only one single item of precise information on John Hu is known. One of the staff at Charenton gives him a warm blanket, of good quality, to ward away the night cold. He tears the blanket to shreds.

-JONATHAN SPENCE,

The Question of Hu

On a bitter cold day in early March 1996, I drive down from my home in Northampton, Massachusetts, to visit with my brother, Robert, in his new home on Coney Island Avenue in Brooklyn. This will be our last visit together for a while, since, in a few weeks, I will be leaving the United States for a four-month teaching position at the University of Freiburg, in Germany. Robert's new home, Park Manor Adult Care Facility, a proprietary residence for some sixty to seventy adults with physical and mental disabilities, is about a twenty-minute walk from the four-room apartment on Martense

2

JAY NEUGEBOREN Street in which Robert and I grew up together in the years during and after World War II. Robert has been transferred to Park Manor from South Beach Psychiatric Center, a state mental hospital on Staten Island, where he has been confined to a locked ward for the past thirty-two months.

Eager as I am to spend time with Robert *outside* a mental hospital, during the drive down, and especially as I get closer to Brooklyn, I find myself becoming increasingly nervous—talking to myself, telling myself to slow down, to take it easy, to just relax. I find myself making an effort to bank the fires of my hopes and eagerness a bit, for not only do I want to be careful not to have my hopes become expectations Robert will feel as pressures, but I am aware that previous departures in my life—to Indiana, California, France, Massachusetts—have invariably been accompanied, in Robert's life, by psychotic episodes and breakdowns.

Robert experienced his first breakdown in 1962, two months before his nineteenth birthday, and he has spent most of the thirty-four years since then in and out of mental hospitals, day treatment centers, halfway houses, group homes, supervised residences, emergency wards, and welfare hotels. For the past half-dozen years I have been writing a book (Imagining Robert) in which I have tried to set down the story of his life—of our growing up together in Brooklyn, of his early breakdowns and hospitalizations, and of our relationship in the years since, years in which I have been his primary caretaker. Robert has collaborated with me on the book, recalling, in conversations and in writing, his life before and after his first breakdown, and, working together, we have chosen the family photos that appear at the start of each chapter, and that help chronicle our story.

Now, on a bright, icy day in early March, a month before Robert's fifty-third birthday, and for the first time in nearly three years, Robert has been released from his locked ward, and—a sweet convergence—on the day he is transferred from the hospital to his new home, I have mailed off the final draft of *Imagining Robert* to the publisher.

I bring things he has asked for: a camera, a deck of cards, marshmallows, some clothes—along with a copy of the book's title page, on which I have reproduced a photograph of the two of us. In the photo, taken in the summer of 1943, when I was five years old, I am sitting in a sunlit field, smiling down at Robert, who—born a few months before, on April 17—sits on my lap. I've kept the photo in an old oval silver frame on the night table beside my bed for years, and during the drive down to Brooklyn some of the peacefulness and happiness I have always found in the picture—some sense of a future that may yet be filled with easy, sunlit days—is with me again. "This is the most beautiful picture in the world," Robert says each time he sees the photo, and he has suggested we use it for the book's jacket.

Despite the sheer misery that has been the matter of so much of Robert's life, I am feeling once again, for him as well as for me, optimistic and expectant. It is as if Robert and I have both been set free this week—Robert from the locked ward where, most of the time these past two and a half years, he has been kept on isolation, often allowed out of his room for only one hour each day. And, the book completed, I am feeling that I have been set free too: from a story I first began trying to tell thirty-four years ago, shortly after Robert's first breakdown, and from the fear, through all the years since, that I might die without having done so.

Robert can now come and go in the world—visit friends, take trips, play lottery tickets, hang out at OTB parlors, eat in restaurants, find work, go to movies, concerts, plays, and museums, and wander the city—he can return, that is, to those things, old and new, that give him pleasure. And, the final draft of the book done, and my three children grown and out on their own (for the previous dozen years I have been a single parent to them), I can leave my home too, and return to my first love: the writing of stories and novels. The people, places, and things that have been roaming the caves of my mind while I tried to conjure up the world Robert and I actually experienced—these imagined and vaguely sensed

characters, scenes, stories, and who-knows-what-else—can now be given their freedom too.

During the year preceding Robert's discharge from South Beach, I have been speaking with people in New York and Massachusetts about programs—for rehabilitation, housing, employment, education—that might be available for Robert once he is discharged, and I have been keeping Robert informed about what I have learned. What I have been discovering is that the world of individuals with mental illness is not at all what it was ten, twenty, and thirty years ago, when most people with conditions and histories similar to Robert's were condemned to lifetimes of hopelessness and institutionalization. It is not even what it was five or six years ago, when I began doing background research for *Imagining Robert*.

I have also been meeting people who share with Robert the fact of having a severe psychiatric condition, and a history of repeated and/or long-term hospitalizations, but who, unlike Robert, have recovered, and have made viable lives for themselves in our world. I have been meeting men and women who have been incarcerated for a dozen years and more in mental hospitals, who have had long-term psychiatric disorders, who have been given up on and abandoned by friends, families, and mental health professionals, yet who are out here with the rest of us, living lives like those most of us live: lives that include college educations, full-time jobs, friendships, marriages, divorces, children—lives marked and informed not by madness and the fear of madness, but by the ordinary joys, losses, and struggles that are the stuff of most lives.

While my discovery of several new and good programs for people with long-term psychiatric disorders does not make me believe Robert will suddenly, at fifty-three, recover into the kind of life he or I might have imagined possible for him twenty, thirty, or forty years ago—that some magical cure is imminent—I am convinced Robert can have a better life than the one that has been his.

When I visited Robert at South Beach a month before, he

4

JAY

NEUGEBOREN

had, for the first time in more than two years, been allowed out of the hospital on a pass. We had eaten lunch in a nearby restaurant, taken a long walk along a deserted beach, played lottery tickets, and passed the time talking and joking about things we usually talk about: reminiscing about the past—about friends, family, and times spent together—and making provisional plans for the future, when Robert would be out of the hospital again.

In the decade preceding his most recent hospitalization, he had done well—his hard times had become less frequent, his hospitalizations less lengthy. He had maintained himself for several years without any hospitalizations at all, and during these years he had spent his days working part time at various jobs in Staten Island Hospital, visiting friends and family in and around New York City and in upstate New York, vacationing in Atlantic City (both by himself and with me), and visiting me and my three children—his niece and nephews—in Massachusetts. At the time of his most recent hospitalization, in June 1993, he had been living with two housemates in a private home on Staten Island, without onsite supervision.

Now, three years later, emerging from the Brooklyn Battery Tunnel and driving along familiar streets, I find myself smiling at the prospect of being with Robert, and at the fact that he has made it back into our world. I drive along Ocean Parkway, where some of our cousins live, and then along a street that borders Prospect Park, a park where Robert and I spent many days together when we were boys. I turn into Coney Island Avenue, and the instant I spot Park Manor, I stop smiling. Damn, I think: We've been here before too, haven't we? I park in front of Robert's new home, a three-story building that looks substantial enough, but which, like the neighborhood, is run-down and dreary.

The sidewalks are littered with garbage and abandoned supermarket shopping carts, local storefronts and buildings are boarded up or shut down with metal grilles, and the thick JAY NEUGEBOREN security door to Park Manor is locked—but to protect the world from the mad, I wonder, or the mad from the world? I ring the bell several times before a man comes and asks who I am and why I am there. I give the man Robert's name, and he opens the door, then turns away.

I step into a large lounge area that reminds me of those dimly lit train stations and shelters where, in old World War Two movies, refugees gathered while awaiting resettlement. The lounge is filled mostly with empty brown plastic chairs, and the chairs, forty or fifty of them, are lined up in straight rows in front of a television set. Except for the chairs, the TV set, and a few long folding tables, the room is barren, the walls a murky dull yellow ("urine-colored," Robert later says). A dozen or so residents sit around the edges of the lounge, immobile, and they look neither mad, dangerous, nor sick: merely old, maimed, and lifeless. I am the only visitor this Friday afternoon, and it occurs to me that, at fifty-three years of age, Robert is going to bring down the average age of the population here considerably.

When Robert appears a few minutes later, he immediately begins offering me gifts—food, used clothing, coupons for cigarettes and magazine subscriptions—and introducing me to other residents. He tells each person we meet that I have written a book about him that is going to be published. He takes me upstairs and shows me his room (bare except for two beds and two dressers), the view from his window (of an alleyway), and introduces me to his roommate, Charles. Charles, a thin man about Robert's age, carries himself stiffly, and his responses—his lack of responses, really—suggest either heavy medication, and/or, my guess, neurological damage suffered early in life. The room, like the lounge, corridors, and staircase, is reasonably clean, and—like the people living here?—in a state of dull, advanced deterioration.

Robert, however, is full of energy, anything but dull and lifeless. He talks nonstop (without allowing me to finish sentences, or to answer questions he asks), shows me each item

7

TRANSFORMING
MADNESS

in his dresser and closet, tells me what I should bring on my next visit, asks me to take photos of him and Charles, asks about his niece and nephews, and where we are going to eat, and how much money he is going to make from our book. He asks about our mother, who lives in a nursing home in West Palm Beach, Florida (suffering from Alzheimer's disease, she no longer recognizes me, or her nurses), and if we should say *Kaddish* for her. He keeps removing his dentures from his mouth (all his own teeth are gone), then putting them back in—in and out, out and in—while he whispers secrets in my ear, moves from subject to subject without seeming transition, and howls with laughter at things I say or he says.

He is unfocused, restless, excited ("cycling up," as his doctors might say), and, when I don't agree with him or do exactly what he says, quick to anger. When we head downstairs and out into the street, for lunch, I glance back at Park Manor, and I think: My brother has gone through all he has gone through these past few years for *this*?

My brother has had to obey all the rules and regulations on his ward for an extended period of time, and he has had to deal with all that has been involved in effecting his transfer (and the transfer of prescriptions, social security payments, savings)—meetings, screenings, interviews, the filling out of forms—along with his anxieties and fears about living in New York City again—to be released to *this*—to earn the right to live in a bare room in a decaying building with several dozen disabled, forlorn, and forsaken strangers, and in a neighborhood where even the graffiti are without flair?

There must, I think, be other and better alternatives.

Although the staff at South Beach has declared that Park Manor is "the best and only" option for Robert, people I have spoken with in the weeks preceding Robert's release (including Marvin Newman, a junior high school friend of Robert's who has been a deputy commissioner in the New York City Department of Mental Health) have warned me about it ("A miserable place," Marvin says, "—the bottom

JAY NEUGEBOREN of the barrel"), and have offered to help get Robert into a better residence. But this will take time, and can be more easily arranged after Robert is discharged from South Beach. First get him out of the hospital, Marvin advises, and then we'll work on getting him into a better living situation.

Robert and I walk along Coney Island Avenue, Robert stopping in stores, introducing me to shopkeepers with whom he has made friends, and checking pay phones for change. By the time we arrive at a Greek restaurant he has chosen, a few blocks away, he is calmer, and we are, once more, relaxed with each other, happy to be together—to be talking, joking, and reminiscing the way we usually do—as if we might be any two brothers having lunch together on any ordinary day.

When, about midway through the meal, I tell him that I've sent off the final draft of the book, and when I show him the title page, he says nothing. He stares at the page for a few seconds, touches the photo of us briefly with his fingertips, then carefully folds the piece of paper several times, pressing down its edges with the palm of his hand. Just before he puts the page into the breast pocket of his shirt, he draws the paper to his lips and kisses it.

In the restaurant we take some photos, and during the walk back to Park Manor, despite an ice-cold wind that forces us to take shelter in doorways, Robert asks me to take more photos. As we get closer to Park Manor, however, he becomes impatient, irritable, demanding. When we arrive, though I tell him that I need to head north for home before rush hour, he keeps telling me that I have to come inside, that I have to visit his room again, that he has to show me things. When I say that I probably won't see him again before I leave for Europe, but that I will call and write, he does not respond, and no matter how many times I say good-bye, or begin to leave, he has more things to show me, more things to talk to me about. When I finally give him a farewell hug and kiss and start down the stairs, he becomes enraged—

eyes bulging, face red, neck muscles straining—and he starts screaming at me.

In front of Park Manor, we embrace again—he kisses me wetly but does not say good-bye—and after I get in the car and pull away from the curb, I look in the rearview mirror and see that he has stepped off the sidewalk and has begun following me. I slow down, and he turns away, wanders into the middle of the street. I hesitate, think of turning back, but see that, his beret pulled tight on his head, he has crossed the street and is heading in an opposite direction, and I think: He is not going to make it.

9
TRANSFORMING
MADNESS

I make a call that evening, to the pay phone in the lounge, but nobody can find him. When I telephone the next day, a social worker informs me that Robert had come downstairs the night before with a belt buckled around his neck, as if to hang himself, had become loud and aggressive, and that—for at least the fiftieth time in his adult life—he has had to be hospitalized.

While I am in Germany I write and call Robert regularly (I also ask friends and family who know him to do the same; during my four months abroad, he receives one note and two calls from others), and before I leave, and while I am away, and after I return, I keep asking the same questions: Why was there nothing better than Park Manor available when Robert was ready to leave South Beach—and why, when people on the staff told me Park Manor was the only and best option available, did I encourage Robert to go along with them?

At the time, their explanation—that they had an arrangement with Park Manor whereby residents could be taken back to South Beach regularly by van for a day treatment program—seemed, for purposes of transition, to make sense. Clearly, having this arrangement made things easier for the staffs at both places. Clearly, too, it made things easier for me.

Although I rationalized my actions, and lack of actions, by saying that as soon as Robert was settled in at Park Manor, I would call on people to help him move into a better situation, now I have to wonder, and to second-guess myself, about not having explored other possibilities, about not having been more aggressive on Robert's behalf.

10

JAY NEUGEBOREN When in early August—my first week back in the States—I visit Robert at South Beach, my wonder turns quickly to sorrow, and to frustration. Robert is happy to see me—he is enormously affectionate, and somewhat less manic than he often is—but he looks terrible (pasty skin, half-closed eyes, stooped posture, shuffling gait, no teeth), and his demeanor (from medications?) unusually subdued and listless. His therapist, Mark Kaplan, sits with us for a few minutes, and when Robert goes to the bathroom, Mark whispers that Robert's "plateaus—his ups and downs"—seem to be coming in shorter and shorter cycles, and that, although they haven't told Robert this yet, the staff is considering trying ECT (electroconvulsive therapy) with him, that another patient on the ward recently completed a series of shock treatments, and "came out quite well."

I am astonished—appalled, really—that Mark is confiding this in me and keeping it from Robert, especially since, an ongoing issue, the staff rarely informs me about anything concerning Robert, and I remind Mark that Robert has had a lifelong fear of ECT. I say that it was my understanding that ECT was used only as a last resort for severely depressed patients, and that Robert has no history of severe depression.

Mark shrugs and says that in his opinion ECT has been "underused."

Robert returns, and announces that his problem with Mark is that Mark is both his social worker *and* his therapist.

Mark says that this is true.

"That's schizophrenic," Robert declares.

Robert and I laugh, but Mark does not, and when Mark says, in answer to a question from Robert about who he is—

"What I want to know is, what is my *identity*?"—that it seems to him that Robert is a Jew and a brother, Robert shakes his head sideways.

"They're not the same thing," he says.

I am heartened to see that Robert's sense of humor is alive and well, and when I call him that night, Robert tells me that, except for Mark's presence, he enjoyed our visit. "He ignored me and just kept asking you about your trip," Robert says. "He was very rude."

A week later, because routine lab work shows that Robert's liver enzymes are elevated, he is transferred to Bayley-Seton, a general hospital on Staten Island, where he stays for a week. After he returns to his locked ward, I call Mark, and Mark tells me that since Robert's tolerance for medications is getting lower and lower, the staff just doesn't know what to do for him anymore, and so they are still seriously considering ECT. When I ask about trying Clozaril, a new antipsychotic medication that has been remarkably successful in helping individuals like Robert who have long-term histories of mental illness, Mark says that since Robert won't agree to take the weekly blood tests that must accompany Clozaril (few patients ever immediately agree to these tests), this is "not an option." According to Mark, Robert is "abusing the phone," starting fights with other patients, and is also, the staff suspects, the patient responsible for stuffing sanitary napkins into the ward's toilets, although no one can figure out how he obtains them.

Robert is also angry with me, and sometimes screams at me and hangs up on me when I telephone ("It's smoking time and you took me away and why don't you adjust your life to my schedule, you goddamn fucking asshole!"). When, however, I call on the first night of Rosh Hashanah, the Jewish New Year, a half-year after Robert's brief stay at Park Manor, he is calm and talkative. We wish each other a Happy New Year—Robert asks that I and my children be inscribed in "The Book of Life" for good health, wealth, and happiness—and when I say, as gently as I can, that I hope, in the

TRANSFORMING

H

coming year, that if Robert wants to get out of the hospital, he will be able to, Robert says softly, "Oh no—I don't want to. I don't want to get out, Jay. I don't ever want to leave. This is my home."

I say nothing except "Oh," and a few seconds later, Robert speaks again.

"It's safe here," he explains.

12

JAY NEUGEBOREN During my time abroad, I have written several short stories, and have begun preliminary work on a new novel. I have also worked on an essay about the care and treatment of people who, like Robert, are judged to be "chronically mentally ill"—those whom the mental health system believes are beyond hope, and beyond recovery. I take up this essay again now, and decide to make use of what I think of as leftovers—material I cut out, or left out, of *Imagining Robert*: passages in which I put forth views on when, where, and why the mental health system was failing, and had failed, along with the ways in which it often gave the least and poorest care to those who were most in need of care.

I had not, in *Imagining Robert*, wanted to reduce Robert's life to an editorial about the mental health system and so, for the most part, I had put aside my analyses and recommendations in order, or so I hoped, to better serve the story of Robert's life, and of the miracle and mystery of that life. For though Robert's life is hardly enviable, it is, still, I wrote, a life at least as full and complex as any, and the wonder was not what had caused his repeated breakdowns and incarcerations, but what, given his life, had enabled him to survive—and to do more than survive: to retain his generosity, his warmth, his intelligence, his pride, his humor, his energy, and his sense of self. This, it seemed to me, remained, as ever, the true miracle and mystery.

Now, however, sad and frustrated that Robert is, once again, living most days on isolation (this is called, by the staff, "reduced stimulation")—and fearing for his future (except for the few days at Park Manor, he has been hospitalized

At the same time, I find myself thinking about madness and of the ways, in life as in language, it is often synonymous with anger. For if love and guilt sometimes conspire to act as my muse, anger—being, that is, quite literally mad—is often, as now, the engine that seems to drive me and to keep me going. If only, I believe, I can make sense of things, of my rage and my outrage—if only I can, in words, explain and show and prove just how bad and unjust things are and exactly what we might do—must do—to make them better, all might yet be well. . . .

Why is it, though, I wonder, that I can at times transform my madness—my often wild, overwhelming, confusing, murderous feelings of rage, frustration, indignation, and help-lessness—into a fuel that fires my prose and my life, while Robert, most times, cannot? Why is it that, similar to each other in so many ways, we have come to lead such different lives, lives in which I am sometimes able to do what Robert seems incapable of doing: to make my imagination and my anger work *for* me instead of against me?

A sane person, I recall our Hebrew school teacher, Dr. Baron, telling us when I was nine or ten years old, builds castles in the air, but a madman—and here was the difference, the answer to the riddle Dr. Baron posed for us—a madman lives in them. While Robert's flights of mind and feeling seem often to unmoor him from this world, the opposite is true for me: When the very stuff of my mind goes flying off, or burrowing down, into places that have never existed, and I live in them for a while—in these times and places that have never been—I often come to feel not only intensely exhilarated and clearheaded, but more solidly grounded in this world. It is as if the very ability to imagine

13

TRANSFORMING MADNESS JAY NEUGEBOREN lives I have never lived—to let memory and desire lead me where they will, and to see lives, lived or unlived, as stories—allows me, often, to get through: to find, to create, and to sustain a life that is, for the most part, both safe and surprising. Why is it, though, I wonder now, that Robert's thoughts, feelings, and memories, when they take flight, lead—as they do for so many others—to a grim life that is sometimes surprising, but rarely safe.

Four months after my return from Europe, on an early December evening, I attend ceremonies sponsored by Boston University's Center for Psychiatric Rehabilitation, at which ceremonies thirteen people, all with long-term histories of mental illness, graduate from a yearlong computer training program. A year before there were fourteen graduates of the program, eleven of whom went on to half- or full-time employment with organizations such as the Boston Symphony Orchestra, the U.S. Trust Bank, and the Lotus Development Corporation.

I sit in a wood-paneled amphitheater with about a hundred guests, and I listen to speeches—by faculty members, by university and state officials, by graduates of the program—and it is as if I am watching thirteen versions of Robert, all of whom, by their testimony, have had histories and lives very much like his, but none of whom are living in isolation on locked wards.

As the graduates accept their degrees, and at a reception afterward, they talk about their years in state institutions, about the abuse and neglect they have suffered, and about how often they had given up hope. They talk, too—something I will hear repeatedly in the months to come—of how doctors told them once upon a time that they would never get well and would have to be institutionalized forever. They talk of how doctors told them that if, by some chance, they were ever able to live outside hospitals, they would have to lead marginal lives—lives in which they should never even consider the possibility of holding down full-time jobs, or of

During the previous ten months, these thirteen individuals—many of whom are married, have children, jobs, families, and homes of their own—have been attending classes at Boston University five days a week, five and a half hours a day, after which they have each served two-month internships. The director of the program, Larry Kohn—a six-foot one-inch, two-hundred-pound man in his late thirties who, with his broad shoulders, deep-set blue eyes, handlebar mustache, and rangy manner, looks as if he might have been a quarterback for a Big Ten football team, or, what he actually was for a few years, a lumberjack in the Northwest—opens the award ceremonies by informing us that ten of the thirteen members of this year's program have already been offered employment for the coming year.

This is good news, Larry says, but what he wants to emphasize tonight is not success, but struggle. He wants to emphasize what each of the thirteen graduates has gone through in order to complete the program, and not only with things any of us might struggle with—the difficulty of returning to school after having been away for a while, or of applying for a job after being out of work for an extended period of time—but with things most of us rarely if ever have to contend with: the mere getting out of bed in the morning and getting to the classroom—navigating a journey across a city via buses and trains when your head is logged down with psychotropic medications and you have a lifelong, paralyzing fear of crowds.

Larry talks about how hard it is for people who have for long stretches been both out of their minds and out of this world to go for interviews when any interview fills you with dread—with anxieties about revealing your medical history, with fears of being rejected and humiliated because of your history—So, can you tell me about those missing years... and what if these mental problems recur while you're working for us... and oh, yes, one other thing: How often have you been

15

TRANSFORMING
MADNESS

violent...?—and with shame for being a person who possesses such a history.

Larry talks about the struggles these thirteen individuals have undergone in sticking with their studies when, in addition to problems that derive directly from the side effects of their medications (drowsiness, drooling, nausea, constipation, impotence, headaches, tremblings), and from their psychiatric condition (depression, mania, visual and auditory hallucinations), feelings of hopelessness, failure, and despair rise up on a daily and sometimes hourly basis—feelings that have pervaded large portions of their adult lives—and often threaten to wash them away.

Larry talks about the key element of any recovery process hope—and when he does, I hear the word in a way I have never quite heard it before: as if it is something tangible—as physically real as a rock or a heart or a river or a car engine.

For the first time in memory I am reminded that hope—like love, like trust, and like faith—is not merely an abstract and most unscientific noun vaguely and loosely used most of the time, but can prove to be a genuine and quite solid element—a palpable force in a person's life and being. Clearly, for people in the room with me, hope has proved at least as significant—as life-changing—as any chemical or genetic marker, as any medication or molecular configuration.

What Larry says is elaborated on by others throughout the evening. Dan Fisher, a Harvard graduate who holds both M.D. and Ph.D. degrees, who was for five years a research neurochemist with the National Institute of Mental Health, and who is now medical director of Eastern Middlesex Human Services in Wakefield, Massachusetts, is the evening's keynote speaker. He talks about his own hospitalizations for schizophrenia, about his journey of recovery, and about how hope—having others believe in him—allowed him to believe in himself again.

In addition to his full-time responsibilities as medical director at the Eastern Middlesex Clinic (and to his life as the married father of two teenage children), Dan also serves as

16

JAY NEUGEBOREN