

Story by Story:

Who I Am, What I Suffer

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By

Robert Arnold Johnson
and Thomas Alderson Davis

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Nothing is so credulous as misery.

Thomas Babington Macaulay¹

And little by little I can come to consider madness as being an illness like any other.

Vincent van Gogh²

A doctor does not treat typhoid fever, but he treats the man with typhoid, and it is the man with his peculiarities ... we have to consider.

Walt Whitman³

One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.

Francis W. Peabody, MD⁴

What we do see, first and last, is the utter inadequacy of mechanical medicine, the utter inadequacy of a mechanical world-view.

Oliver Sacks, MD⁵

Attentive listening is itself therapeutic, for one encounters many fine tales. Few great books expose the human condition more clearly than a patient who has permitted one to look deeply into his or her eyes.

Bernard Lown, MD⁶

Stories are the primordial means through which we make sense of and convey the meaning of our lives.

Craig Irvine, PhD and Rita Charon, MD, PhD⁷

¹ *History of England*, Vol. 3, 472. The author is speaking of Charles II. This quotation was brought to our attention by one of our readers, Mary Anne O'Neil, PhD, whose father, Lawrence J. O'Neil, MD, was a general surgeon in New Orleans from the mid-1940s to the mid-1990s; he recited the quotation often.

² *Ever Yours: The Essential Letters*, 665. We are grateful for an article that pointed us to van Gogh's observation: Buckley, *Vincent van Gogh ...*, 626-7.

³ A quoting of Whitman, after a conversation with him in January 1888, by Dr. William Osler. See Michael Bliss, *William Osler: A Life in Medicine*, 159.

⁴ *The Care of the Patient*, 882.

⁵ *Awakenings*, 273.

⁶ *The Lost Art of Healing*, 9-10.

⁷ See Charon et al. (Eds), *The Principles and Practice of Narrative Medicine*, 110.

HILARY (the principal character): *What does materialism remind you of?*
It's a faith.

Tom Stoppard⁸

⁸ *The Hard Problem*, scene 7.

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PREFACE & ACKNOWLEDGMENTS

Many readers skip the Preface. So, believing this one especially important to the purpose of the book, we're going to hazard an injunction: do not skip this! Consider our enticements. We'll be brief. We'll unpack a word, "uncanny," that will appear in the text from time to time. We'll be informal.

We two authors live and work in a small city in the southeast of Washington State, Walla Walla. During a psychiatry residency in Philadelphia, RAJ became fascinated by catatonia, about which we'll have much to say in this book. Later, when he and TAD became acquainted, RAJ would sometimes pester his new friend. "Hey, we should write a book about the philosophical implications of catatonia. The condition makes a joke of the way we ordinarily talk about mind and brain, when we talk as if we know what we mean." TAD would listen in a kind of quizzical way. In 2013, Danielle Ofri came to Walla Walla to give the McClellan Lecture on Humanity in Clinical Care, and we two joined her in a symposium after the lecture. TAD's query about one of her vignettes in *What Doctors Feel* seemed to take root, maybe itch would be better, in his own mind. We decided to proceed soon thereafter.

This work has unfolded, literally, with each chapter taking its prompt from its predecessor. And the starting point, largely at TAD's insistence yet very soon an intuition we held in common, had to be a story. The first story must take up the suffering imposed by catatonia, the uncanniest of all human states. Why catatonia? Because it had been the initiating focus for the discourse between us. We learned as we went that a story must set the context for each new unfolding. We must find our way, set our thinking, within a context of stories.¹

One early product (chapter 3) of the unfolding we speak of here is a phrase, "medical prejudice." The experience of its popping up when it did felt *uncanny* to us at the time, and in the Oxford English Dictionary sense that goes like this: as if supernatural, mysterious. We came to make use of this word, though, in an entirely different setting within the book, that of describing the *experience of the onlooker* in response to someone who has become catatonic.² TAD holds the view that the uncanniness of catatonia

¹ RAJ is the author of the four pieces of fiction (Chapters 1, 4, 6, and 12) in the book.

² We often substitute "bizarre," but in the sense of the uncanny.

resides in the way the condition moots or elides words like “mind” and “brain,” something he attributes to the *anxiety of the enigmatic*. Salman Akhtar, in a wonderfully economic commentary on the word uncanny,³ includes the sense that the boundary between alive and dead has been breached or has become fuzzy. This sense seems to fit catatonia well: the body lives, and yet the person (*who* previously owned it) is gone (as if dead, albeit temporarily).

Thinking through the story in chapter 1 of a person prone to spells of catatonia, TAD in chapter 2 introduces a way of talking that sets aside speaking of “mind” and “brain,” and that way of talking is one we give a name to in chapter 3: *who/what talk*, or *WWT*. From there, we go on to examine stories of mood disorder (chapter 4), personality disorder (chapter 6), catastrophic brain injury (chapter 9), and physical illness (chapter 12). In each case, for each story, we show how useful and illuminating the deceptively simple language of *WWT* can be.

As we go, the idea we found uncannily cropping up in chapter 3, that of *medical prejudice*, takes on elaboration, too. So, we’ll conclude with it. What has been the origin of medical prejudice in the presumptions and habits of physicians and other caretakers? What are its implications and effects? What is the basic form of its remedy? How does *WWT* help guide us there?

We have the idea that this book may be read in more than one way. Just for example, before the customary tactic of cover-to-cover, some readers may gain from first reading the five stories (chapters 1, 4, 6, 9, and 12) one after another. That way, the challenges faced by their characters are glimpsed through an intuitive comparison of similarities and differences, so that the subsequent encounter with the visions of psychiatrist and philosopher, as each adjusts to *what* a character suffers within a context of *who* the sufferer is, and each author adjusts to the prompts provided by the other, may be more easily, perhaps even differently, understood. Something so straightforward as the footnotes provides another example of how to read. The value of the footnotes, which we ourselves put a premium on, will not be the same for every reader. For a busy clinician looking for the gist of what we’re driving at, they may be ignored, the longer ones at least. For a student of philosophy, psychology, or psychiatry, they will be important.

A final point about reading. Chapter 2 will be difficult for those wanting to skim. For some readers, it will be a first exposure to philosophy-in-process, the kind of philosophizing this book is based on. Our advice: slow down, be patient; this way of thinking has a kind of internal music within it;

³ Salman Akhtar, *Comprehensive Dictionary of Psychoanalysis*, 299.

once you get the tune, you'll discover its essential simplicity. It is an unveiling of the book's first principle: the nature, lingo, and "grammar" of *WWT*.

Acknowledgments

Thomas Alderson Davis. I want to acknowledge and thank Julia Ireland, whose detailed comments on my reading (chapter 2) of Zack (chapter 1) helped sustain and develop my first intuitions. In addition, I wish to thank the founders of the James McClellan Annual Lectureship, Humanity in Clinical Care (see <http://www.mcclellan.lecture.org>): Robert Arnold Johnson, Kenneth Isaacs, Joseph Wujek, and Casey McClellan. Dr. Johnson and I participated together in a symposium following each of these lectures for a number of years; it was then that our first inspiration for *Story by Story* took hold (see Preface, above).

Robert Arnold Johnson. I have been sustained and inspired during the preparation of this book, as in so many other aspects of my life, by my spouse, Susan Eileen Pickett. To Dimitri Markov, David Lynn, Rajnish Mago, Kenneth Certa, and Salman Akhtar, who were each responsible in different ways during my psychiatric training for exciting my interest in catatonia and my wonder for the persons stricken by it, I offer my gratitude. And I want to thank Max Fink, too, for his tireless effort over so many years toward educating the psychiatric community at large about catatonia and for giving me personally on the telephone unhurried time for discussing its treatment in a particularly trying circumstance—the latter something far enough in the past I'm sure he has forgotten, but I never will.

And the Authors together. Thank you, Carol Cassella, novelist and physician: your commentary on an earlier draft of this work caused us to double its size, expand its reach, and clarify its purpose. We are deeply indebted, too, for the careful readings (sometimes several of them) and invaluable suggestions of Mary Anne O'Neil, Patrick Henry, Susan Pickett, Anahi Johnson, and Richard Lyle Johnson. We thank our copyeditor, Daniel Le Ray, for his dedication to the integrity of the work. Our collaboration with Rebecca Gladders and her colleagues at Cambridge Scholars Publishing has been a delight from the beginning.

SECTION I.

**A STORY OF CATATONIA:
WHO-LESS, TEMPORARY**

CHAPTER 1

ZACK Z. 'S STORY

My name's Zack Z. I'm black and 27.¹ I'd like to know being in love and what it's like to marry and live every day with the same person. On the other hand, these things may not fit any routines that I can devise for them, which is worrisome. I reside, and always have, in North Philly near Einstein Medical Center, but I need to say right now that everything I say about myself that's identifying—my name, age, city, neighborhood, job, etc.—is made up. Curiosity about being in love and being married, these are true, and other things about me are, too, but hardly true of just me.

Generally, I have trouble lying. My distress is not too, too bad if I can think about it carefully ahead of time, plan it out, make of it a sort of ritual. I like ritual. What I don't like is making up stuff on the spot, especially stuff about me personally or stuff I have to imagine about somebody else, what another might have on her mind. Because I know I'm making up stuff, it's hard for me to think somebody I'm lying to wouldn't know that. Sometimes I wonder if being caught in a lie, somebody saying, "You're lying, you son-of-a-bitch!" bothers me more than most people. I don't have much idea, or even a good guess. As I say, thinking about what other people think or feel isn't easy for me. If the person is right there with me and I can bounce some guesses of mine about her mind off of it, so to speak, then I do pretty well (though it took me a bunch of years practicing); it's more like a ritual. But a lot of people don't want to wait around for me to do that, especially women I might feel attracted by. The circumstances have to be special.

So why am I going to this bother of telling a story about me while I hide myself at the same time? It's an exercise. I've assigned myself this task, of telling my story, or *a* story, as a way of celebrating that I'm talking, communicating, at all. You'll think that's odd. You haven't, I'll bet, experienced times of total, or nearly total, uncommunicativeness. These

¹ The narrator, as stated here, is a fictional black person. I, the author, am white. Some may interpret our relationship as a moral impropriety, an appropriation of black American culture for a selfish purpose of my own. I hope the story itself dispels that notion.

periods wherein I don't talk, these get me in trouble—they're sort of famous in my neighborhood. It's the trouble they cause, when the will to make speech just vanishes, not any discomfort or anguish that I suffer at the time, that I can celebrate the absence of. Wow! Have a look at these sequential negatives! Writing a story of myself minus myself, minus speech that brings on trouble that I can later celebrate the minus of...

In my family, meaning my mom and my sister, I get ribbed a lot about being organized. A plan is good. It's been like that with me always. Mom used to say I was a bit slow beginning to walk because I had to have a plan for where I would be going during the whole of the next month, or maybe year. The same thing could explain why my speech was slow coming on, too. I had to know what to say for a long stretch. Which is—I'm not kidding—how it was. I said not a word until I was almost four and a half. A lot of worry was going on in the household. Doctors were consulted. I seemed, mom says, very curious about things, especially objects, so the doctors figured my intelligence overall might pass muster. I could not provide a lot of gratification for my mom, my sis, and other caretakers, like my Aunt Bess, because I wasn't ever much for returning smiles or coos or playing patty-cake. Early on I appeared pretty content, well, more than that, very content, with playing alone. But I did listen keenly when mom read to me, which was often. And that, of course, was one reason she figured my hearing might be normal despite my silence. I would tug several times on her sleeve were she about to get up from reading: my way of pleading, it would seem. One day the thought came into her mind to count the tugs; the answer was 10, and sure enough the tugging was always in groups of 10—it was a ritual. She admits that not until then was she able to recognize the extent of her love for me, when now she knew that, really, I wanted her company and attention. Love, until then, I suppose, was presumed more than experienced. Anyhow, when I finally spoke one day, when she was about to get up once more from reading to me, I went on without pause for almost an hour by reciting a series of the stories, one after another, that she'd been reading those many, many months. As if that had been my plan all along. And I gave her a hug, which caused another realization about me. I loved hugging. At least one kind of reciprocation turned me on. She told my sis about her hug-discovery, and from then on life with Tess, my sister, who's six years older, was changed forever I'd guess: we began hugging a lot, which goes on still.

I work as a theorist of numbers. I'm a doctor, literally, of numbers, awarded my PhD in mathematics at the age of 23 from Temple University. The jump on graduate school came about by finishing a bachelor's degree

at the same university at 20, which I could do because my high school, the famous Central High School, itself confers a bachelor's degree if you work really hard, which I'd done. And now I'm a member of the department that awarded the last two of my degrees. In short, I'm Temple from the beginning, or near it, and, I hope, will be to the end. It runs in our family. My mother did her undergraduate study here, as well as her law degree. My dad, who died shortly after my birth—he was murdered by associates of a notorious criminal he was about to prosecute—had gotten his law degree here, too. And both parents grew up in North Philly. The place is, if ever this saying's true, in my blood. The only times I'm away are for talks that I'm invited to give. Stanford, MIT, Caltech, UCLA, Harvard, Cambridge University, and the Technical University of Catalonia (Barcelona) have each asked me to talk and I've agreed. I didn't want to agree, but I did, after some serious persuasion in these cases from my department chairperson. I have turned down a bunch of others. It's leaving routine, the expectedness or sameness of the usual, that bothers me a lot. It's often told that Immanuel Kant, the famous German philosopher, was so regular in his daily rounds that shopkeepers could set their clocks according to his passing by. Well, I just may be Dr. Zack Z. Kant of North Philadelphia.

And here's the way I connect my love of planning and routine to my love of numbers. From the beginning, I loved numbers. And I've always been able to recall prodigious strings of them. Mom says I spoke of little else between ages 4 and 15, which was pretty off-putting to my listeners. When I discover something new, or that seems new to others, about numbers, to me it was there all along, you see. It was in *the plan* but it's a part in the plan, a routine in the plan, that you have to think about routines to grasp onto. It's thinking about plans and their embedded routines that permits seeing more about them. Numbers, as I understand them, are just a special way we plan, routinize things, but in my case and in the case of mathematicians generally, we've gotten more interested in the routinizing itself than in the things. This came out in a conversation I had with an old grade-school acquaintance on the street awhile back. I'm going to paraphrase things and admit, as if you wouldn't see it on your own, that I'm messin' with him some. "Hey Professor," he'd say, "how many fancy rides you own these days? I hear you do a good, good job at Temple! Still you not be with any woman in particular? A fancy ride might solve that problem!" "I'm glad you ask, 'how many?'" I reply, "because 'How Many?' is my special field; it's what I think about all day, and part of the night; it's what I got hired to think about and teach about. But here's the thing, if you go around thinking about 'how many?' all the time, without

thinking ‘how many what?’ like you do, if you lose, or in my case ignore, the ‘what’ in the ‘how many?’ you become odd, maybe crazy a little... like me. I have to stop and think about your question awhile—that’s odd isn’t it? Then it occurs to me I got no ride at all. And next it occurs to me that I do have rides but the ‘how many?’ is not a positive number. In other words, it’s not one ride or more than one ride, but it’s not zero rides either. In fact, it’s a negative number of rides. Maybe something like -3 or -4. Here’s how I’m thinking. No rides are in my possession. But that’s not really zero. It would be zero if I wanted a ride, if it was the next thing I will buy, plan to buy, for me myself, yet right now don’t have even one. But I don’t want to buy one for me at all by comparison with other wants. As I think about it, I see that I want to buy a ride each for my sister, my aunt, and my mom more than for me. So that’s how I get to my -3 answer; it’s just a guess, because wants like these are hard to express in numbers. That’s the best I can do with your question. Now, yes, I agree that I’d be much more likely to go out with women if I had a fancy ride. But I’d go out once with each of them in that ride and each would find they didn’t want to be there anymore. Why? Well, as you can see here, I’m pretty odd, a little crazy. A special woman for me would have to like being with someone odd and a little crazy, and I’m not likely to find that person by owning a fancy ride. In fact, I think it would get in the way of finding her.”

Now it’s true that the routines we number theorists continue to find—that have been there all along but not seen before—make the business of numbers spooky. We presume that the whole numbers were just invented one day, metaphorically *one day*, to count stuff. “Hey, I killed two old lions since the last full moon, whereas you killed one only. Therefore, I deserve a vacation. I get to stay near home with the ladies, dig some roots, pick some berries, while you hunt another lion!” And so forth. You can see readily how counting facilitates planning. Yet if counting was the beginning, and the number system simply flows from that beginning, how did all these plans within the plan of counting, these routines that take some hard thinking to see, get in there? Take some of the facts—we number theorists established that these are facts, that’s our job—about prime numbers. I won’t get into this now, but there is a whole lot to say—I teach a special seminar to graduate students—about prime numbers. It’s hard to think those innovative persons, and maybe at the start it was just one person, had anything about prime numbers in mind when they, she, or he began counting dead lions. It’s as if the plan of numbers, with all of its embedded plans and routines, was in the world as a thing, too, not just a way of thinking that we humans made up so that we could get a day off

from hunting now and again. Well, if the number-thing *is*, it's something we can point to, touch, only in our minds. My guess is that it's a manner of speaking, really, that's at issue here. We often mean, when we say "thing," something apprehended with one of the ordinary senses, like touch or sight. But giving that ordinary meaning to "thing" is just a way of speaking; we can include the number systems and other nonmaterial stuff in "things" if we just agree to talk differently. Numbers are my favorite way of talking, the first that I developed any trust in. I don't have to look a person in the eye when I talk numbers. I have trouble looking persons in the eye. If I do, it makes it hard, almost impossible, for me to think at the same time. But I'm getting off the point. I think a number system *is* just like anything else you can talk about pointing to. With talk we find things as real as the things in the world we can point to wordlessly. Here I am already, again, talking about talk: a full circle, perhaps the most elegant of all routines.

But the routines of and within numbers are hardly the only routines that entrap me. Some of my other routines are so rigid, so inelegant, that the word *ritual* is better than the word *routine*. A lot better. A brief example. Every day of high school I'd walk a block from our place on N. 16th Street down to the corner of Kemble Park, then straight ahead one long block along its eastern side to W. Olney (as I go, I spend exactly five minutes in the park, kicking leaves if it's fall, snow in winter, etc.); then I'd hang a left and proceed to N. Broad, cross to the other side, and turn right to go south, but only a few doors to Johnson's Deli, where I'd buy a breakfast snack from Marsha, a plump and pleasant older woman who was there every weekday and would have the snack set aside for me (Johnson's would let me pay every Saturday morning for the whole week gone by since the ritual was so unvarying). Marsha would always say the same thing; I think she has my disorder, too, which, if you haven't guessed by now, is autism. "You make my day, Zack: always I can count on you; Mr. Z. is Mr. Reliable! And a good thing, since life is such a mess! Don't you agree?" To which I'd nod. But I knew I was trapped somehow. Other kids could change things, change how they got to school, where they studied, where and what they ate, what they said in exchanges with people like Marsha. And yet if something came up to alter my "same-old, same-old," I'd get anxious and angry, really irritated. I dreaded graduating from high school because I knew, of course, I'd need to set up another routine to get to Temple University and back every day. It will hardly surprise anyone to learn that when I'd finished my degrees at Temple and was about to come on faculty I changed as little in my daily routine as possible. I had to stand in front of the classes I taught, of course, but this wasn't so hard because I

got practice doing it little by little while still a student. I don't mind giving talks in front of students or other people because, guess what? I have a chance to plan what I'm going to say. And where numbers are concerned it's as if I don't have to actively remember anything. It's more like reading off a blackboard in my mind. And I'm pretty patient with questions, so students like me. No doubt they talk about me as strange, but that's OK because I'm used to that. A lot of autistic kids, I've read, get bullied when they're young. But I had an advantage, Well, several. I was large for my age from kindergarten onward, and that's still true today: 6 feet 4 inches, 240 pounds, and pretty strong. Plus, I have a peculiar indifference to pain. I feel it well enough to say what it is, but it's not a big deal. I don't think I ever cried, not even once, when I injured myself as a kid, when I fell from a stool or tripped and fell on the sidewalk, skinned my knee or elbow, like that. So, I have little fear of fighting. Guys sense this: they are not overly anxious to assault me. I can take, amiably, quite a bit of teasing, I suppose because I agree with a lot of it: I am an odd dude; I can see that. Once in sixth grade when one kid's teasing was getting to be a little much, I asked mom for advice. "I think you'll have to confront him, look him directly in the eye—and it's very important to look him right in the eye—and say quietly, 'Stop!' He'll know what you mean; don't bother with explanations." It worked. I didn't have to hit him. And very rarely since I've made use of this exact technique. Still another advantage is that my father was, and is, famous in North Philadelphia, even these years later. He had stood up to some really bad guys. So, bullying his kid was uncool. And Central High School is filled with ambitious students, from a scholastic standpoint, so bullying isn't something many of them have much time for. I'm off track again. After nodding at Marsha, I'd proceed along Broad to W. Somerville, turn right and cross back over to the other side of Broad and proceed down W. Somerville to my high school, eating my snack. And reverse things on the way home, including the stop at Johnson's Deli. At least I could change to a different snack, an afternoon snack. But... yes, it was always the same one.

One of the things kids found oddest about me growing up was my talk, and now I mean how I talked, not whether I talked. From the start, and I mean "start" literally, my talk's been on the side of formal English, rather than on the side of talk as practiced by kids my own age, and by other people around me, what some call *spoken soul*, an especially musical version of street talk. An occasional *soul* phrasing sneaks in, but mainly it's as if I were speaking from a television set—and from a so-called "high-end" channel, like PBS, at that. Which is, probably, how it came about. I learned, during the three early years I wasn't speaking (to the

consternation of everyone around me), how to speak from watching television. Plus, my mom herself often talks at home in a relatively formal way by comparison with many black women, and the same is true of her sister, Bess. It's as if, when I began to talk, I'd already settled in on *how* I would talk. And that way of talking was, in my case, already a routine that I would not or could not readily give up. Most kids, of course, unconsciously and soon, begin to mimic the way kids their own age talk. Now, my mom can speak *soul* whenever she wants. I can't. I can't get myself to do it. In kindergarten, other kids looked at me funny when I talked. I asked mom about this, and she said, "If you can't find in yourself the will or the capacity to talk like other kids, you'll need a way of explaining. Otherwise they'll think you're stuck up, and kids hate it when other kids act stuck up. You might try complimenting them for how good their talk sounds to you, but then say how you're unable to do it yourself. You try, but it comes out wrong, as if you're trying to roll your Rs as an Italian or Spaniard would, but you are one of those speakers who just can't roll an R (they exist). So, you stick with what you can do, even though you know it sounds really funny. And do your best to look the person in the eye when you're going through this; that will help." This is what I did. I worked up my own version of what I've just quoted from mom, memorized it, and began to make use of it: admittedly, it was awhile after kindergarten. Mostly it's worked. And, as I've said already, my large size may have given it weight—ha ha!

And now you see another of my quirks. I'm well known for laughing, too long and too excitedly, at my own jokes. A hard routine to break. Comments show up on the evaluations my students fill out at the end of every course. Things like, "Dr. Z. has a really strange sense of humor; sometimes he is the only one laughing, which makes me feel bad for him because he's so nice to everyone." Guess I over-credit the humor in my jokes in more ways than one. And yet I don't get it. They seem so funny to me.

OK, it's time to develop the main theme, the theme of talk, *whether*, not *how*. And this does not have to do, directly at least, with my speech being delayed in the first place. No, this is different. It comes on sometimes abruptly, sometimes with a buildup over hours. The first time was when I was 17, a few days after graduating from high school. My aunt, Bess, made the generous gift to me of a vacation trip to Boston to visit Harvard and MIT, because she thought that someday I might want to study or work at one or both of these great universities. She bought plane tickets for me, mom, and herself, with the idea that we'd have a good time together for a few days, looking over these two places and others nearby, like Lexington,

Concord, and Fenway Park. Speaking of Fenway Park, baseball statistics are a thing with me: I am very, very good with them. I entered in contests sometimes from about age 10, and I'm the winner in most of them. I'm no good at playing baseball, or any other team sport, but I sure know a lot of baseball stats. The Phillies, of course, are my team, and from an age beginning just after I began to talk. But I'm distracted. Bess had read about a regiment of black soldiers from Massachusetts, the 54th, that had fought in the Civil War, and their leader, Robert Gould Shaw. She wanted to see, and wanted us to see with her, a bronze memorial to Colonel Shaw and the regiment; it's located on the Boston Common. Her husband, Jess, had been killed in Vietnam near the end of American involvement there, when she and Jess were just 20 years old, so she had tenderness in her heart for soldiers who died in battle, as Colonel Shaw and a whole lot of his men did in 1863. But I was terrified. I had never been out of North Philadelphia for any reason. Every routine and ritual would suddenly be inoperative, and I was having a hard-enough time just thinking of how to construct a new routine for getting to Temple and back each day come fall. I told Mom that I just could not go; she and Bess should go alone. "But this is Bess's gift to you, Zack, not to me. The tickets are purchased. I think we all three must go."

And that's when it began, a spell the doctors a few days later when I was hospitalized at Einstein would call *catatonic*. In a way, I'm grateful for catatonia; it prevents me from feeling something like complete terror, the final terror, the feeling of being overwhelmed, not being able to keep up, therefore about to be *schmooshed*, rubbed into nothingness, by events out of my control, wildly out of my control. Catatonia, then, is peaceful for me, unlike the state that immediately precedes it, as if time has become irrelevant, put on hold—I have frozen it so nothing bad can happen: a kind of omnipotence, I suppose. The impulse to act out of my own force, or agency, may disappear, such as when I have nothing to say (even though I'm aware of people talking to me, or to others, and sometimes recall long stretches of such "listening in"), nowhere to go (I'm motionless)—even my bowel may have nowhere to go (i.e., I come down with truly awful constipation), and nowhere to look other than that "where" I'm looking at now (if we speak of *now* in such a timeless state we must mean a continuous state of it). And then it, the urge to act, comes flooding back and may erupt in some really crazy stuff. I suppose *time* reappears with it. Such an epoch first got me in the hospital. I suddenly stripped off all of my clothes and went screeching out onto N. 16th; I had nothing in my mind, so far as I know, to say or declare; the screeching seemed an adequate communication, given that it was combined with nudity. The police picked

me up within minutes I'd guess, my mom having called them, and I was off to the ER at Einstein. So, it's *all* will, and some nutty action to go with it, but no purpose; or *no* will, no action, and no purpose; or, and this feature of the catatonic state I haven't mentioned yet, there's *one* will, one action, and one purpose—and these are confined to opposing whatever someone is asking. In this latter state, I might resist the doctor bending my arm, for example, during her examination of me. Or the opposed may be a diffused locus of expectation or authority, such as when I dashed naked out into the street. My intentions, in other words, become either nil or extremely simplified. What do these states within catatonia feel like? Well, not much. Feeling is sort of suspended, and that's, in fact, what I'm grateful for, because the alternative seems so awful; maybe it's like having a dead mind but a live—albeit very slow or very excited—body. I say “maybe” because, of course, nobody can know literally what a dead mind is like.

The dread I feel about catatonia is bad—*that* I feel. You may be surprised. “But you just said that you are grateful for catatonia!” The thing for me to explain here is that both are true: gratitude and dread—but not at the same time. The dread, once I had that first spell, is, more or less, always with me. The gratitude exists as a theoretical feeling and is limited to the escape from the terror that precedes catatonia, as I've gotten into already. It's theoretical because the transition from terror to catatonia is seamless: one replaces the other; but I *imagine* that I'd be grateful if I was in a live mind rather than a dead one once catatonia commences. But my dread is not theoretical; it is very real. I dread the consequences of having been catatonic, still again. When you learn, and somehow I always do learn, what you were like in the eyes of others, the eyes of family, the eyes of doctors, the eyes of nurses, the eyes of police officers who were called to haul you away to safety, the eyes of neighbors who may have seen you, the eyes of friends and acquaintances who've heard descriptions of your state And then there are the questions when you resume your classes. Where were you? What happened? What's it like to be in a psych ward? (I have little idea because I don't have organized thoughts or feelings during the time; I'm not myself.) And from some people there's pity, which is not easy for me to bear. And from others wariness, caution, or outright shunning: also, not easy to bear. And there's my self-pity. “I've always been odd anyway, and now I have these spells that are so damned bizarre. Why must I be afflicted with the craziest stuff? Will I ever find someone other than my mom, my sis, and Aunt Bess to love me, really love me? How could someone who's not obliged to love me do so? How could they pull it off? Could I pull it off, if I knew someone like me? Could I love

me? Is it fair to say that when I'm catatonic I'm disgusting? I'm *either* odd or disgusting, one or the other—that's it, one *or* the other!" And so forth.

Five spells of catatonia have befallen me altogether. I hold out some hope that the fifth will have been the last, but then there's the dread I just spoke about. One of my friends in the math department at Temple is pissed off that I've had to go through all five spells. He thinks my psychiatric care has been suboptimal. We disagree. But the story of why I've had all five spells tells some things about us humans. The first time around the diagnosis of catatonia was made on my arrival, and for that I'm thankful, because in many places it isn't: the correct diagnosis can be delayed for a long time, even (not at all rarely) missed altogether. But in my case the next step, the one after diagnosing the catatonia, was messed up. The inpatient team declared that I was schizophrenic, that I must be schizophrenic, since I had presented with catatonia. Schizophrenia is a psychotic disorder; unsurprisingly, its treatment is antipsychotic medication. For me, this, in retrospect, simple-minded formulation—*catatonia means schizophrenia means antipsychotic medication*—was to consign me to the hell of four more catatonic spells in the next seven years. (Keep in mind that for me the hell of catatonia is not the state itself, it's afterward facing the shame of having been through it, learning what I've been like during the spell.) My brain is poorly tolerant of antipsychotic medication, any of the total of six that would be tried. I won't go through them by name, one by one, because it's too depressing, but one from the 1st generation, or *typical*, antipsychotics, and five of the newer, second generation, or *atypical* antipsychotics were tried.

Part of the problem may have been that the psychiatrist in charge of my care would change, over and over. Residents in psychiatry and medical students, for the most part, looked after me on the inpatient service. Residents are young—well, usually they are young—doctors who are in training to become full-fledged psychiatrists. They mean well; they are smart; they cared about me. Ditto for many of the students who'd get involved in my care. Would I have gotten the same solicitude had I not been young, like them, and a budding math genius? I don't know, but probably not. Sometimes I'd overhear one of the students or residents whispering to another: "He has an IQ above 160! He's predicted to be the next Isaac Newton!" Or some such. We're humans: we're doctors, we're non-doctors. Each one of us can overlook the persons in the people we encounter. I'm autistic: if anyone knows about losing track of persons in favor of things, I do. My care in the outpatient clinic, too, would be by a resident. And I liked every one of them. But about the time I decided I really liked my doctor (I'm exaggerating a little here), the resident doctor

would finish her sojourn in the outpatient clinic, move on to another venue of the hospital, or another hospital, for her next clinical experience, and someone new would replace her. This ceaseless changing of the guard really, really wore on me. You can imagine, given what I've said about my dedication to routine and sameness. I think one reason nobody, for a long time, seriously questioned the diagnosis of schizophrenia is this: I did not have the same doctor long enough for him or her to really get into the struggle of ego-strengths required for questioning the authority of what had already been laid down: *catatonia means schizophrenia*.

What would happen became a pattern. I'd be given lorazepam (Ativan) on admission, and lorazepam is fantastic for putting an end to catatonia. If the dosing was vigorous, I'd be on my way to recovery in an hour, and completely well in several hours. If the dosing was timid, it might take several days. I never required ECT (electroconvulsive treatment), which is very good also for catatonia, because I'd get well so fast from lorazepam alone. On that first admission when I was 17, an antipsychotic drug, risperidone, was commenced a few days before my discharge from the unit. Then, as I remember, lorazepam was rapidly tapered down, so that it was risperidone alone when I went home. The questioning I faced from two guys I knew on my block about why I had run out on the street naked was awful. Finally, I said, sort of shouting, "Look, I went crazy! Isn't that obvious? Do you think someone wants to go crazy? Asks for it?" Then I got quiet and said, "Knock it off. That's my advice." And they did. Still... There was a twelve-year-old girl, Kelly, four houses down from ours that I was tutoring in math twice a week; she was very fond of me, but her mother said she couldn't have me for a teacher anymore; Kelly called to tell me, sobbing on the phone... I'm getting off track. My breasts began to swell, and they were painful. My thinking was a little slower. The resident at the first outpatient visit took my history and looked at my breasts. Then he called his supervisor. The supervisor—"attending" is the word often used—said I should tolerate these side effects and continue the medication. I was dismayed. The painful, swollen breasts were now producing little bits of milk at times. Even for an odd kid like me, obsessed with numbers more than with girls, a kid who had never asked a girl out, or never had been very tempted to ask a girl out, this business with the breasts was a strain on my self-esteem. I told the resident that I'd try to keep on taking the risperidone, but I didn't know for just how long. He was sympathetic. I had the feeling that, had his supervisor not requested otherwise, he would have made a change in medication or stopped medication altogether. The latter could not have been worse than the way it came out. A week later, with simply the minor stress of making

a trip down to Temple to see if I could begin to lay out a new routine, I became catatonic again. Hey, this trip is one that has just nine stops, local stops, on the Broad Street Line: that's all there is to it! But when I came into the house after the return trip I was not speaking, my mind was in the "dead zone"; I lowered my pants, took my dick in my hands and began to pee, and to pee with some plan it seems, because I went from one piece of furniture to another; then I became immobile, staring down at the dick, still holding it. When the paramedic unit arrived, my posture could not or would not be altered: the techs had to lift me up as I was and lay me down on the stretcher: same posture, but now horizontal instead of vertical. As soon as I arrived on the floor of the inpatient psych unit at Einstein, I was given a shot of lorazepam in the butt. Lo! One hour later I'm fine. No more risperidone was given, but a new antipsychotic was started and a few days later I was discharged. Pain in the breasts receded as the swelling resolved. But a new problem: my appetite became humongous, and I began to gain weight, a lot of it. Three months later a third spell occurred; again, the stress that brought it on was minor by comparison with spell #1. And now a third antipsychotic medication; this time I'm sent home with lorazepam to take three times a day as a second med. I lost the weight I had gained with the second antipsychotic, and I'm pretty good then, just a really dry mouth all the time, for several years.

The fourth spell was brought about when the oral defense of my doctoral dissertation was rescheduled to an earlier time, by a month, than I had planned on. One of the members of the examining committee was hostile to me. My dissertation advisor had warned me about this person, who is not a numbers theorist, and who had not completed his PhD until the age of 35 after several years working as an engineer. As stresses go, this one was not terrible. Still, it was enough to bring on #4. By this time, my mom and my aunt have read a lot about schizophrenia, and they have concluded that I just don't have it. They think I'm autistic instead, and that antipsychotic medication is possibly making catatonia more likely rather than less. They argue vigorously with the attending psychiatrist, Dr XY, the same person who insisted that I continue with risperidone those years ago, but he prevails—says that this newfangled notion that catatonia can complicate mental illnesses other than schizophrenia, or purely physical illnesses for that matter, is "poppycock!" My Aunt Bess, who is even more assertive than her sister, the lawyer, leaves him with this declaration. "OK, one more go-round with still another antipsychotic to fix a psychosis that never seems to show itself. But if catatonia comes back, that's it: no more antipsychotic, or we're going to Penn, or to Jefferson."

And I'm leaving out a new person in my life. One of the medical students caring for me during this fourth admission, Lizzie, went out on a limb. She told me one day, "I've heard your mom and your aunt in discussions with our attending, and I think they're right. Your mom and aunt, I mean—I think they're right. I got curious and I started looking through the literature, which there's a lot of. Dr. XY's view is outmoded. All the experts on catatonia now hold the view that schizophrenia is not the most common of illnesses to serve as a scaffold for it, a 'predisposition' it's called. No, mood disorders, especially mania, are much more common. But, in my opinion, you don't have either schizophrenia or a mood disorder, you have autism, I'm certain of it, and so are your mom and aunt. Your mom has done a lot of reading, and she says the features of autism in your case could not be more classic. She's right. You want to hear something funny? Do you know that the residents and students here talk about you as if you're destined to be the next Newton? Well, I've looked into the biography of Isaac Newton. I think he was autistic, too! Now here's the thing. There are papers coming out now that report catatonia as a complicating feature sometimes, maybe fairly often, in autism. The problem is that they're about children, because that's where autism gets talked about. Look, my resident, who agrees with me, and I have scheduled a private meeting with Dr. XY. We're going to do our best to convince him that you don't have schizophrenia and never have had it." That conversation was in the evening, just before Lizzie went off duty. The next day at noon she came to see me again, and broke into tears. "Dr. XY would hear none of it! Says he's been looking at patients with catatonia for years and years, and that it's one presentation of schizophrenia. End of story. I'm so sorry, Zack. I don't know what to do now. Please don't report what I've just said to anybody beyond your family. If word gets back to Dr. XY, he could try to get me dismissed from med school, and he might succeed. He's pretty powerful around here."

Of course, when I got home, on a career-high sixth antipsychotic by this time and a higher dose of lorazepam, I did talk to mom and Aunt Bess about Lizzie, her viewpoint, and her failure to persuade. Mom's view, and Bess went along with it, was this. "Dr. XY is no idiot. I think he's wrong. He thinks he's right. But none of us knows, independent of opinion, for sure. I do believe Dr. XY has your best interest in mind—he is worried that, if you are not on antipsychotics, you'll be sicker than you've been. So, let's stick to the agreement we made, or sort of made. One more go-round of antipsychotic. If there's another spell of catatonia, even just one more, no more antipsychotic, just lorazepam." More years went by. The dread never left me. I was doing well in my job. The word "job" falls

short. My job is numbers. But numbers are much, much more to me than a job, if you haven't guessed. Numbers are my salvation and always have been. The joy I get from thinking about them, the praise I get from the academic world for writing about them, the admiration from students I get for teaching about them, and the prestige for our department, within the university, yes, but beyond the university, and beyond Philly, for that matter, that I've helped attract, these make the considerable oddness I present to the ordinary guy or girl not a stigma but a kind of lovable specialness. Otherwise I could not bear the terrible dread I've described about catatonia. And I see no need to further explicate what I mean by "could not bear."

I hear from Lizzie from time to time. She calls me on my mobile phone to check in. She did finish med school, and then began a residency in psychiatry at, of all places, Einstein Medical Center. I was not surprised. I am very, very pleased that she chose psychiatry. She has a gifted amateur's interest in mathematics and subscribes to a couple of the journals.

Just one side effect from the last antipsychotic became known to me, and that was late in its tenure. I made a new friend, a woman. A girl in my class at Central High, Sheila, real smart in math and science, and possibly, like me, autistic, became a chemist at Temple. One day I ran into her on campus, and she said that a good friend of her mom's, a woman named Theresa, who was a physicist at a private college not far from Temple, had heard about me and about my work. She wanted to meet me. I had some trepidation; I was not sure why, because I, of course, interacted with female colleagues all the time, not to speak of female students, both undergraduate and graduate. Sheila gave me Theresa's phone number, and a week later I called her. "Oh, I have wanted to meet you for a few years now!" These were her first words. She mentioned one of my papers on prime numbers, which indeed did go back a few years. "Do you drink coffee? Can we get together that way?" I told her that I was addicted to espresso, maybe because it helped keep my attention-deficit in check (like a lot of autistics I have some ADHD, thankfully pretty mild in my case). She laughed. "Maybe I have that, too. Maybe you'll be able to diagnose me." We met at the closest Starbucks. Theresa is white, single, plump, buxom, sexy, smart, and affectionate. And 30 years older than I. She's a theoretical physicist, and in the last two decades has mostly thought about, like a lot of others in her field, how we might re-conceptualize quantum mechanics and relativity in such a way as to get them into one theory. She has a daughter who's a physicist, too, now in Los Angeles. (It's her daughter who got me, later on, out to Caltech and UCLA to give talks).

Theresa's marriage ended in divorce decades ago, and she has lived alone since in Center City on Locust. We were friends from the start. "You have trouble looking directly at me," she said soon after we sat down. "Is that part of your illness? ...

I'm sorry. I've heard that you're ill from time to time. People refer to you as 'a mad genius.' Did you know that? Are you offended? I think I must be frank. It's my nature. And I think it's best when I meet a new friend to get this part of me right out on the table." "I like your frankness," I replied. "That way I don't have to guess what might be on your mind. I have a struggle with that sort of thing. I'm autistic. That's why I have the problem with making eye-contact. It's common with us autistics. I've worked hard to overcome it, but when I meet someone new it just pops out all over again." (Notice that by this time I'm very much at ease with referring to myself as autistic. And I'm confident that I don't have schizophrenia, even though I have not broken my "contract" with Dr. XY about taking the antipsychotic.) We, Theresa and I, met for coffee a few more times, and then she invited me to come to her house for dinner. "I'm sure I'm not the cook your mother is, but I can do some simple things fairly well," she said. "I'd like to come," I said, "but I need first to practice a few times getting there and back on my own, because I have this difficulty with getting to places that are new to me. It's part of autism." "OK," she replied. "You can stop to visit for just 30 minutes or so until you get comfortable with the trip and with my apartment; then we'll plan for you to come to dinner." So that's what I did, and before long I was having dinner with Theresa at least once a week, sometimes more. The trip is easy, really: the Broad Street Line to the Walnut stop, then a ten-minute walk. And Theresa introduced me to wines, which I soon learned to enjoy. One evening, after still another talk about the Cantorian infinities, she took my hand—we were sitting together on a couch—and said, "Zack, would you like to kiss me? Am I too old and fat to seem sexy to you?" "You are not old and fat," I said; "To me, you are very, very sexy, and, yes, I'd like to kiss you. But I've never kissed a girl or woman on the lips, and I've certainly never done anything beyond kissing. So, you will have to show me these things if you want to. Maybe that makes me pretty unsexy to you." "Hardly," she said and laughed. "You make me so horny that at times I have an orgasm just sitting close to you. That's fun, but I'd much rather do the real thing, have you inside of me. Do you want to try to do that?" "Well," I said, "you've taught me one hell of a lot of physics; I don't see why I couldn't learn some biology, too!" Theresa and I began to have sex. And it's divine. I had no idea. But, and finally I'll get to the point I started with here, I found that I could get erected only every week or two, and each of us

wanted to fuck more often than that. One day she said this, “Zack, I’ve done a little reading. I think the antipsychotic medicine you’re taking is causing a kind of partial impotence. A guy your age can be expected to have sex daily, or nearly, so you see what I’m getting at. Now, it’s OK. I was having sex with no one before you; what we are doing is one hell of an improvement on that. But... I’m just wondering. You’ve said that you doubt whether the drug is needed, and in fact you’ve had the thought that it may make another catatonic spell more, not less, probable.”

Thus, I had still one more thing to balance against the “sort-of promise” to Dr. XY. A week or two later the business got decided for me. The chairperson of mathematics at Harvard had been pestering me to come to Cambridge and give a talk. Until then I had been turning down such invitations. Harvard, it seems, felt no duty whatever to honor my “no.” The chairperson there called my own chairperson, Nancy, and asked her to pressure me. She was happy—OK, I’m being a little sarcastic—to oblige. “Zack, you’re too important in mathematics now to sit here in North Philly like a recluse. I cannot force you to go give this talk, I want no part of such an action, but I can beg you. That’s what I’m doing. I’m begging!” I consulted my mom, Aunt Bess, and my sister, Tess. Their views were of one mind. “Only you can decide. You know the risk, which is that of a recurrence of catatonia. And there’s risk in not going, which is an important, but probably not fatal, blemish on your career.” So, I brought the matter to my sexy friend, Theresa. By the way, my family had learned about Theresa. One morning mom had said, “Zack, I think you must be seeing someone. You’re gone at least one evening per week, often more. And that’s new for you. Do you want to tell me about it? Or, if you don’t, don’t. I’m sure you will when you feel the time is right.” I told her the whole story right away, including the fact that we, Theresa and I, were having sex. And the fact that Theresa was 30 years older. She smiled. “Well, lucky you. And lucky Theresa! A scientist and a mathematician enjoy love and ask nothing more of each other than that. Not for me to interfere, that’s for damned sure! I’m happy so long as you are.” As I mentioned, I brought the business of the Harvard talk to Theresa. She listened carefully to my reasons for going and my one good reason for not going. And then she said, “I’m afraid you must go, Zack.” It was her wording, so similar to mom’s those years ago when the same place, Harvard, was at issue. I excused myself to go sit on the toilet. And that’s where Theresa found me an hour later when she worked up her courage to force her way in after spending 30 minutes talking through the door, hoping to hear me give reassurance that I was alright. I wasn’t. I was mute, staring at my dick, fixed in the pooping position. Theresa called the

paramedics, of course, and told them to take me to Einstein, where I was known. And she called my mother, explaining the exact sequence of events, including what she had said that seemed to set off the spell. Then she caught the Broad Street Line to Einstein herself, where she met mom for the first time, as well as Tess and Aunt Bess.

The fifth time was the charm. So far. And this time there was Lizzie, now the chief resident in psychiatry, a person with some power. She had the inpatient team order a good dose of intramuscular lorazepam, which soon ended the spell. “No more antipsychotic for you, Zack,” she announced gaily. “And this time your record will no longer contain the diagnosis of schizophrenia. As I believe I’ve told you once before, you don’t have it and you never have!” She sent me home the next day, and on lorazepam alone. She also thought I could make the trip to Boston so long as I was sure to take the lorazepam with me. And she prescribed some extra to carry. “If you get especially anxious, begin to feel overwhelmed, take an extra pill, for good luck.” A week later I flew to Boston, my first airplane flight. Theresa went with me. She asked to go when mom was there with us. Mom smiled. So did my Aunt Bess when she heard about it. So, did I. I am very, very fond of Theresa. I cannot say that I’m in love. I have explained that, and she has said, “That’s good! I’m too old for you to fall in love with. Plus, falling in love is no guarantee of friendship. What we have is, for us, strange math nerds that we are, more precious.” Perhaps. We’ll see. Routine can be a blessed thing.