

The Myth of Solid Ground: a memoir for Hannah

“The healed Heart shows its shallow scar”*

On my left forearm, close to my wrist, there are two white scars so faded and tiny that you might not notice them even if I pointed them out to you. They’re the remnants of a bite mark I received on Christmas Day, 2001. One scar is a short white line and the other is roughly circular, the circumference of a molar.

And of course they’re not all that remain of my daughter. I have stacks of pictures and videos, school art projects, doctors’ reports, activity charts, MRI images, Special Olympics medals. I’ve kept five or six pieces of her clothing, including the sneakers I wear when I take the dog for a walk along the rutted ATV trails west of town. I even, ridiculously, have her brown-velour La-Z-Boy rocker, ripped and stained, the underlying structure so decrepit that when you lean back in it, the broken laths curve around to conform to the shape of your body, as if in capture or embrace.

But it’s the little scars that comfort me most, because they’re always right there with me, like pale tattoos, and they’ll be there till the day I die.

*All chapter titles are first lines of Emily Dickinson poems.

“Speech is a symptom of affection”

Nancy: It’s morning now.

Henry: That’s right. This is part two—“Hannah Awake.” Nancy:
The sequel to “Hannah Asleep.” How old is she today?

Henry: She’s a week and a half old today.

Nancy: Uh-huh. And she’s lying in her daddy’s arms... Henry:
She’s a senior citizen by now. She’s getting up there.

Nancy: She doesn’t do much yet.

Henry: But we expect great things from her later on.

Nancy: We try not to rush her.

Henry: Okay, so—

Nancy: Let’s get a close-up of her feet... Okay. You have to lift up the bottom of her nightgown.

Henry: Lift it up? Really?

Nancy: It won’t kill her.

Henry: Okay.

Nancy: She has very large feet.

Henry: Proportionately, that is.

Nancy: For such a small child.

Henry: And very long fingers.

Nancy: Wait, let me move in on those fingers... She’s breathing now. That’s one of the things
she does very well. She also yawns and grimaces and snorts. Oh, and wait till you see when she
gets the hiccups—that’s a real treat.

Henry: We want to build to that.

Nancy: Yes, that’ll be the climax.

Henry: She's freshly bathed.

Nancy: In her little blue outfit. She has a lot of little blue outfits. We called her Danny for six months of the pregnancy. But we're very happy to have her just as she is. We're very, very pleased.

Henry: See, now, she's sucking her thumb.

Nancy: Oh, let's see.

Henry: Get a close-up of the thumb-sucking.

Nancy: Okay.

Henry: Good strong sucking reflexes. She's obviously a genius. She has the talent to bring the thumb up to the mouth—

Nancy: That's right. A lot of kids this age wouldn't even know they had thumbs.

Henry: Mm-hmm. This is incredibly advanced.

Nancy: Probably most children—

Henry: Most children don't start thumb-sucking till they're sixteen, seventeen years old.

Nancy: She does a lot of things that I'm just amazed by. Everybody in the nursery was jealous, all the other little babies. They didn't say so, but you could tell.

Henry: This is clearly an Einstein baby. So, are you a genius or what? Yes, you are! You're a genius baby!

Nancy: She looks just a little quizzical, a little suspicious.

Henry: A little on the cross-eyed side there, but—

Nancy: Well, but that'll pass, it's perfectly—

Henry: That's perfectly normal, nothing to worry about. See, she's moving her arms now.

Nancy: Yes, it's like some sort of Asian martial arts. Isn't she wonderful? Also, she's very, very clean.

Henry: This is as clean as she gets.

Nancy: Yeah. Oh boy, she's really performing now.

Henry: She's like a three-ring circus here, she's kicking, she's sticking her arms out.

Nancy: Wow.

Henry: Get this girl on Johnny Carson.

Nancy: Yeah.

Henry: Oh, and there's a little cooing noise—can the microphone pick that up?

Nancy: I think so.

Henry: Okay.

Nancy: Okay.

Henry: Well, I think we've run the gamut of her—

Nancy: The gamut of her tricks? All right. Say a few last words before we cut?

Henry: Um. I think you got a real hell of a show there, Ma.

Nancy: Don't curse in front of the child. Okay, here we go. This is "Hannah Gonshak Grows Up, Day Twelve," signing off.

“Who never lost, are unprepared”

We were living in Blacksburg, Virginia, at the time. Two years before, and just a couple of weeks after Henry and I got married, we’d moved there from Denver, where we’d attended graduate school together. I’d been offered an instructorship in English at Virginia Tech. It was my first real, full-time job, and my first five-digit income—\$18,000 *per annum*—which made us both feel so giddy and reckless that for the first year we rented a ludicrously big, under-furnished old house. This was a mistake, no doubt—it turns out that even in 1986, \$18,000 wasn’t all that much to live on—so after the lease was up we devolved to a modern two-bedroom apartment a few blocks from campus.

Even so, it was an era of conspicuous consumption. I started buying underwear in packages of six instead of picking out irregular pairs from K-Mart bins. Henry took out multi-year subscriptions to *The Nation* and *The New York Review of Books*. I got my hair cut in salons instead of doing it myself. We had our grad-school-days posters (Picasso, Van Gogh, John Belushi in *Animal House*...) professionally framed. Cable TV, flannel bed sheets, a fake Tiffany lamp. What heights were left to hit? It seemed, at last, the perfect, peerlessly logical moment to begin a family.

I myself am the seventh of nine kids, and as a child I was sure I wanted to have at least that many myself, when I grew up. Twelve, I thought. Enough for two teams. (Back-yard sports were our *raison d’être* back then.) As life went on, I acceded to the practical, and by the time Henry and I got married we’d settled on having four children, or thereabouts. (I’d have preferred six, Henry wanted two, *et voilà*. If only all life’s compromises were so amicably forged.)

Funny how, when you’re young, you think you can map out your life like that. I think we’d also counted on having twin Pulitzers by the time we turned thirty. And an antique walnut mantelpiece to set them on.

“I’m nobody! Who are you?”

From an old diary:

November 18, 1987: *This week we found out I was pregnant. I don’t know how to talk about what a strange thing that is to hear, the way it changes everything... We’d thought I was pregnant over the weekend, and when the nurse confirmed it Monday, I cried for happiness. I drove right away to school to tell Henry. When I told him, he hugged me—oh, you see how it all sounds? Just the ordinary picture—I can’t really tell you how it feels, and maybe the truth is that it feels like it feels for everybody.*

One of the things I know already is that this baby, however much it will mean to me and Henry, will be just an ordinary thing to most people. It’s almost shocking to think of it—most people, looking at my pregnant body, or later my baby, will not think, “Miracle!” No, they’ll think just what I think when I see their babies—that is, “Isn’t it funny how they all look like Peter Lorre.” But knowing that, and knowing that none of what I’m going through is new, doesn’t make any difference. It’s still a miracle--a beautiful, crazy, thing.

This may be the first time in my life when I’m not worried about anyone else’s view of me, and I guess that’s simply because the gap between the intensity of my feelings and the indifference of the rest of the world is so vast that it seems, somehow, silly even to think about. Besides, this is a time to isolate myself, me and Henry and this little embryo. I really don’t want other people thinking of us at all.

For me it was the first lesson of maternity—and maybe of adulthood itself: that the essential truths of my real life were universal, yes, but also internal, private and, despite my relentless efforts to put them into words, inexpressible. Hannah—even in deeply buried, 4-6 millimeter form—had managed to teach me this. And her second lesson came the next day:

November 19, 1987 [5 weeks pregnant]: *“I’m getting a glimpse of motherhood even as I write this—that choice you’re always making between being yourself and being a good mother. You’d think they’d go together, but they don’t always.”*

I’m not sure just what I was talking about in that entry—maybe having to give up heroin? (Just kidding.) The only ways I remember my life being different in those early stages were that I was

sick sometimes, that I stopped drinking coffee and alcohol, and also that I carried myself a bit more carefully, like a waitress with a full tray. My posture got better. I took deeper breaths. But I was getting a glimpse of the future:

January 23, 1988 [3 months pregnant]: *I wonder if I'll ever find time and discipline to write again. I was never disciplined before, and now I'll have an excuse, something maybe I've partly longed for. But once there were people who believed in me (and I believed in myself, once), and now those people, if they knew I was pregnant, would say, 'Well, there goes that career.' And I'd be dismissed, and maybe they'd be right.*

Apart from that, I need somehow to see my own value in a world that doesn't value me at all. I went through some of this already, when I got married and lost the mystique of defining myself as a single writer, a writer at all. Somehow I lost some writerliness there, and I'm losing even more now. I realize this doesn't have to happen... Sometimes, though, I worry that I won't even be a self anymore. I already feel that. I'm just a vehicle, anymore—no control, no freedom, less and less me, more and more baby, every day.

And my thoughts—quite typical, I suppose—toward the end:

June 23, 1988 [8 months pregnant]: *I have the feeling that if all this lasts too much longer, I'll go crazy. Henry must feel the same way, maybe for different reasons, partly. He's eager to see his baby too, but also eager to see me a bit less monotonous and needy. (I'm just not sure that'll change when the baby comes.) I'm slow and awkward and tired. He has to take care of me sometimes. I have a hard time thinking of anything but babies—I'm not very stimulating company. He feels guilty for wanting to escape me. He wishes it could be like it was, in the days when I centered my life around him, took care of him, kept house and cooked, pampered him. There's a tension between us—the whole thing is like a bomb ticking—four weeks left. But we don't mistake it, usually, for some larger problem between us. No, we just muddle through it, keeping the conversation going, keeping busy as we can, getting through.*

“Water is taught by thirst”

Henry and I had always had a rocky romance, except without the “romance” part. Our first date—September, 1981--was no date at all, but, rather, as he called it, a “study break.” The University of Denver was hosting a double bill that Friday night: Hitchcock’s *Psycho*, followed by *An American Werewolf in London*. I’d seen *Psycho* before, of course, and so had Henry, though every twist and shock still, quite literally, bounced him off his chair. Honestly, I’d never seen the like of him before—squinting at the screen from behind trembling, shuttered fingers; holding himself still and tight, as if bracing for a plane crash; and at one point letting out a shriek that made a guy in the row ahead of us spill his popcorn.

As for *American Werewolf*, I liked it well enough. Nonetheless, neither Henry nor I will ever forget “the incident,” when, as that movie’s cartoon carnage reached its climax, the college kids around us (our “peers,” as it were) started clapping and hooting in neanderthal pleasure, the jolly mobbery of which reminded me, quite naturally, of the Hitler Youth. As was my wont in those young days, I followed up this comparison by starting to cry. The louder the students whooped, in fact, the louder I sobbed, plunged deep in grim despair for the future of mankind. Henry, who had never seen the like of *me* before, had no idea how to respond. And all through the evening, between his terror and my tears, I suppose we both couldn’t help but wonder to ourselves if we’d made the mistake, yet again, of linking up with a lunatic.

Nonetheless, we got along okay. Our senses of humor meshed well, as did our taste in music and movies, and we shared the same partly mock-horrified, partly truly-horrified reaction to Reagan’s version of America. Moreover, we were well matched intellectually, and spent some of our favorite times engaged in a variety of grad-schoolish philosophical and literary arguments. He, for instance, was a boldly confessional writer who espoused a Wordsworthian “egotistical sublime,” while I leaned toward Keats’s ideal of “negative capability,” and thought of writing as a way to witness the world while remaining as invisible as possible. Henry was Walt Whitman, brash and expansive, sounding his “barbaric yawp over the rooftops of the world.” I was Emily Dickinson, quietly finding microcosms in the smallest domesticities.

But while you might think such friction would make for some steamy goings-on in the boudoir, the reality was that the first time we had sex—late on a December night after I’d just spent three

hours helping him edit his final term paper, and by now we were bleary-eyed, numb—the act felt more obligatory than anything else. After three months of “study breaks,” it seemed we’d simply run out of other things to do. The sex was animal-like but mechanistic—the way you’d imagine sharks would do it. He stared at me unnervingly as we lay on his dorm-room bed, sheets off, lights on. Unwilling to be conquered, I stared back. It felt like a mimed version of one of our arguments, both of us staking our claims, neither of us conceding a point, each of us left feeling there were topics that might have been covered more fully.

We spent the next five years together, living together for most of it, a monogamous couple who shared an intimate, invigorating friendship but never, ever got the hang of romance. We loved each other, I’ve come to know for sure, and for most of that time I considered myself “in love” with Henry. Still, looking back, I wonder how much of that was just a projection of a deeper, less targeted longing to be in love. We might have been happier with other people, maybe. And yet, whenever I came up for air and looked around, I never saw anyone who I thought could challenge me more, or be a better day-to-day companion to me, than Henry could be. As much as I longed for romance, it seems I valued our meeting of minds even more.

And yet, of course, I did, I did, I did long for romance. And I’ve never really had it, not to this day—but if I had had it, it would be long dead by now, no? Isn’t that the way it works? Romantic love fades, like a rose in winter, etc.? Better, then, to live on with your longing unquelled, because then the feeling will always be there, ready—eager—to be summoned whenever you can’t think of any other way to feel alive. In the course of my life this seems the one conclusion I’ve come to: that longing, and even heartache (and maybe even the deepest of griefs?—but let me get back to you on that one), is a valuable thing—at least when compared with no feeling at all.

The moving in together was my idea, the marriage was my idea, the baby was my idea. Henry went along, mostly, I suppose, because he couldn’t think of a better plan. I came to realize, eventually, a couple of years after Hannah was born, that Henry tended to think of me as his “first wife” (my phrase)--that he figured that someday he’d meet his *real* love, his soulmate, and then, with a suitable pang of guilt and regret, he’d leave me for her. We were both romantics, you see. We both longed for that magical connection, but we were never able to find it with each other. What we did find—eventually—was something different, something maybe even bigger,

and certainly more lasting, than romance. My right hand, after all, isn't in love with my left hand, but their awareness of each other, their interdependence, their thought-free collaboration as they type these words—I'm not sure how much more vital a bond can get than that.

Still, we fought a *lot*, Henry and I, for years and years. Before we were married, and afterwards, and after Hannah was born, and after the diagnosis—it wasn't dependent on circumstances, though circumstances could make it worse. He punched his hand through a plexiglas partition once—needed the E.R., stitches, everything. Another time, I ripped up his entire stash of Penthouse magazines. He shoved me a couple of times. I tossed his clothes out the bedroom window. To make me feel bad, he got drunk and rammed his bicycle into a tree. To make him feel bad, I banged my head against our bedroom wall. He flung himself out of my car once, though not while we were moving. His clock radio—symbolic because it was, literally, the only thing he'd been able to furnish when we moved in together: I threw it across a room, but with a sliding, sidearm motion, so that it wouldn't actually break.

And there you have it. What we lacked in romance, we made up for in melodrama. Looking back through it all, now that we've moved some short but important distance away from such volatility, I still can't decide whether our still being together, after thirty-some roller-coaster years, is an astonishment or an inevitability.

“The suburbs of a secret”

I gave up my instructorship in the summer of 1988, a month before Hannah's birth. “Gave up”—that makes it sound like a loss, when really I was eager to leave. Though I like it well on occasion, teaching has never been a vocation for me the way it is for Henry. Henry took my place full-time, though only after a bit of departmental finagling, since he was officially considered overqualified for an instructorship: he had a Ph. D now (he'd finished his dissertation during the two years I spent working), while I just had a Master's Degree, and colleges are always afraid that Ph. Ds won't stay long enough in an instructorship, that they'll be perpetually on the lookout for a tenure-track job instead. (Which, of course, Henry was.) Whereas, if you have just a Master's, they know quite well the trap you're in, and smack their lips in glee.

Me, I was trapped by something else entirely, but it was a trap of my own making, a welcome trap. Ensnared by love, that's what I was. Corny but true. A series of diary entries, each in its entirety:

July 26, 1988 [Hannah's six days old]: *Well. As I write this, I—you'll see what I mean—*

September 6, 1988 [Hannah's two-and-a-half months old]: *My life is one long interruption. This—*

September 16, 1988 [Hannah's three months old]: *Okay, so here's what happened—*

Then finally, on September 26, 1988, I turned 30 years old, and maybe Henry gave me some time to myself as a present, I don't know. At any rate, there are a lot of words in that day's entry. I recap the day of Hannah's birth, from the little click that went off in my head the moment my water broke, through the meticulous monitoring of contractions, the hospital check-in, dilation, pain, breathing, pain, the urge to push, "carrying high," episiotomy, pain, blood, forceps....baby! "The most painful experience of my life," I wrote, but also:

Still, it was so full and rich, and romantic somehow. And since then I've looked back on it fondly—for certainly it was one of the very few times in my life I've been so clearly the center of attention, with so many people helping me, with my husband putting his own needs aside, and for once not thinking of me as utterly competent and invincible, for once worried about me, focused on me. I don't dwell on this—it would drive me crazy if I did—but there haven't been many times like that for me, when I wasn't the caretaker. And of course, since that night there've been no times at all, not one, when I wasn't taking care of someone—all that attention to me gone for good now, I think—but that story comes later.

It took a day or two before I really felt like I was her mother. They'd bring her in for me to nurse, and I got to be with her awhile, sing to her, look at her, try to make contact somehow. My affection was there from the start, and then soon enough there came an overwhelming sense of devotion—with the same sort of warm sudden release I feel when the milk lets down. My whole life changed, and I wanted to dedicate all of it to making her happy. I made long quiet speeches to her, in the middle of the night in the quiet hospital room as I held her close in bed. I told her how I loved her and would spend my

life trying to help her grow. It seemed the most natural thing in the world—total self-sacrifice. I still feel that way sometimes, but now it's intermittent, it has to rise up from among feelings of loss that are sad, scary, frustrating. But in those earliest days my devotion was unequivocal: I myself didn't matter anymore.

“Henry hasn’t always been willing to commit himself,” I write a few days later, in a flutter of understatement cultivated not just by my silly, inborn optimism but also by the assumption that Hannah would be reading this journal one day, that she was my primary audience. In real life, my husband was in a state of shock and denial that would last, to one degree or another, for the next seventeen years and beyond.

My first memorable awareness of this was when he invited a quartet of high school buddies down to Virginia from New York to “see the baby.” In the weeklong course of their visit, these guys, including Henry, rented movies, ordered pizzas, reminisced about the horrors of high school. Nobody, to my knowledge, considered doing the dishes. The vision I still carry in my mind is of staring out the sliding glass door to the balcony, swaying rhythmically side to side as I held two-week-old Hannah, who was screaming nonstop for reasons I couldn’t yet bring myself to give up all hope of ever discerning—as, on a court on the far side of the apartment complex, the five guys played basketball. And while such a nightmarish flashback would seem to belong to the category of those one can remember only bitterly, that’s not really how I feel about it anymore. It wasn’t even, exactly, how I felt at the time.

No, what I felt in those early days—and, for that matter, throughout the years that followed—was mainly a kind of wonderment. How did he do it? How could he retain, if not exactly the same lifestyle as before, at least the same frame of mind? For me, the hot Virginia summer had witnessed a revolution, or, at the very least, a coup d’état—with Hannah as my own personal, chubby-cheeked little Pinochet. I was so very, very tired—for, despite my diary’s hopeful predictions, Hannah wouldn’t begin to sleep through the night until she was five years old—that I was, quite literally, hallucinating. (Luckily, I soon came to enjoy the hallucinations—I was always analyzing their details, keen on deriving insights from their weird, subconscious clues.) Not only didn’t I shower or brush my teeth most days, I rarely even got dressed. Instead I wore a series of men’s XXL white t-shirts, which hung down to mid-thigh, and nothing at all underneath, for some eight months straight. Even for visitors, sometimes—I’d lost all sense of

the social graces. I was a blowsy, bovine woman who smelled like a mixture of talcum powder and sour milk. I smelled like Hannah, in fact, and she smelled like me, and we spent hours and hours on the bed or the floor together, focusing our eyes either on each other or on the same glinting object I dangled above our heads. I moved when she moved, and slept when she slept. And when nothing else would soothe her, I nursed her, because that always, always worked. I nursed her for uncountable hours every day—uncountable because it was an on-and-off, continuous process, broken only late at night when she would finally fall asleep, and I'd heave myself back to bed, only to awaken three or four hours later to her piercing cries, at which point I would pull her into bed with me and we'd nurse again, on and off, till daylight.

Meanwhile, Henry despaired. Over and over again he would say to me, "I just have to get used to it." It made no sense to me, that sentence. If a hurricane were blowing our house away, would he be just sitting there, clinging to the arms of his La-Z-Boy, and shouting over the wail of the wind, "I just have to get used to it"? But pretty soon I realized it wasn't like that for him—that he wasn't caught in the hurricane, he was watching it on TV. Watching it miserably—because it was, indeed, his house that was blowing away, his life that was lost to him forever—but what else could he feel besides helpless?

A month or so into our new life, in an atypically daring, self-noticing mood, I signed up for an aerobics class at the YMCA. Twice a week, I'd leave Henry alone with Hannah while I attended the hour-long class. (I put on pants for this, in case you're wondering.) Inevitably, each time I came home, I'd find Hannah wailing in her crib, and Henry in some desperate, cowering stance, either in a far corner of the apartment, or next to the TV with the sound turned up loud, or else out on the balcony with the door pulled shut behind him. That I kept going to the classes anyway was a testament to a sort of last-ditch self-determination I've noticed in myself now and then over the years. Those two hours a week were the only reliable moments in my life, in those days, when I could become some version of myself again. The cooling-down periods, in particular, when the music would slow and soften and I lay on my mat stretching one leg at a time and then letting it fall to the floor with abandon—those five-minute segments at the end of each session remain among the most luxurious experiences of my whole life.

Henry had choices I didn't have. He could sleep through the night. He could wash in the morning, he could linger over breakfast, he could get dressed (though not always in clean

clothes, because no one was doing laundry these days). Then in September he went back to a full-time, challenging job, which led him naturally and maybe reasonably to believe he had the right to spend his nights and weekends not working at all. His life was, in many ways, easier than mine. Yet, sometimes—I'll talk more about this later, I'm sure—I wonder if he missed out on things he might have loved. If I myself had ever felt for a moment that I had a choice like his—that I could follow my own straight-ish, self-directed line, and consign Hannah's care to some wiser and more reliable person than I believed myself to be—well, then, maybe I'd have done it, I can't say.

But then I wouldn't have known it all in the way I do now, I'd have been like Henry for most of his life with Hannah, on the outside looking in. Whatever time I'd have spent with her—and I should say right now, Henry himself spent a lot of time with Hannah, over the next seventeen years, and especially near the end of her life—that time would have felt just a bit artificial, a bit like “babysitting.” Hannah and I would never have smelled alike, or known the same lullabies and folk songs and show tunes by heart, or watched the moon make its leisurely arc across the midnight sky. I'd never have been forced to study Hannah's every move as if my life or hers depended on it, to know her in a way that no one else in the world ever would, or to glimpse, at least in quicksilver, breathtaking moments here and there, a flash of real, primal connection between us. And all this was the beginning of a feeling I got, which later became an idea that I've only just lately begun to feel sure of: that life finally starts at the moment we decide we have no other choice. Till then, I think, we're all just hanging out, killing time.

“The Future never spoke”

Diary entry, November 11, 1988:

I am still in need of two things—sleep and free movement. I wish she'd go places more readily. I wish she'd get a little more placid. I compare her to other babies I know who are her age—and she's the wildest of the bunch. They're all lumps, still, at four months, sleeping, or just staring out, flat on their backs. Hannah was never like that—she's so eager to be getting somewhere, so frustrated that she can't. But she's just learned to roll from back to stomach, so maybe she'll be moving soon. So anyway she's the wildest, the hardest to handle of all the babies, but also the biggest, strongest, most alert and most beautiful.

Researchers performed an experiment in the mid-90s: they studied home videos of first-birthday parties. Half of the babies in the trial would later be labeled "autistic," and half would be considered normal (or, rather, as we say in the trade, “neurologically typical”—a term I love because it makes normalcy sound so utterly déclassé). The researchers monitored the videos for four aspects of a typical one-year-old's social behavior: pointing, showing objects to others, looking at others, and responding to the sound of their own name. And just by counting up those little signs they could tell, with almost perfect accuracy, which of the babies would later be diagnosed as autistic.

A few days ago, for maybe the second time since the actual event, I re-watched the video we made of Hannah's first birthday party. I watched it closely, perched on the edge of the coffee table, which I'd pulled up close to the TV. I also listened hard, and rewound parts of the tape several times to try to hear bits of background noise—mostly things people were saying to each other while, in the foreground, my perky, younger self talked to the camera. The scene appeared in the middle of a much longer movie that dipped sporadically into Hannah's first eight to seventeen months. The birthday scene lasts, maybe, five minutes.

Henry does the filming, which begins with Hannah sitting on the floor of our Virginia apartment in a pointy party hat, rubber band beneath her chin to hold it on. In the background you can hear the light conversation of Matt and LuAnn—good friends of ours in Blacksburg—who'd had their own baby, Luke, four months before I'd had Hannah. Henry's saying, "Look at you, Hannah! You're in your birthday hat! And you know why? 'Cause it's your birthday! What do you think of

that? You're one year old today!" With mild interest, Hannah's looking his way—amused, as always, by the excitement in his voice as well as by the video camera that hides his face.

LuAnn, out of view, says, "You're going to be saying this same stuff to her when she's eighteen, and she's gonna roll her eyes and say, 'Oh, Dad!'" Then you can hear me calling, "Okay, here we go!" and Henry swings the camera around so that for a moment we see Matt and LuAnn over by the dining table, with Luke, in his own pointy hat, standing half-hidden between them. Then the camera focuses on the kitchen doorway, and I walk out carrying a frosted bundt cake topped with burning candles. Various ooohs and aaahs, and somebody asks, "How many candles are there?" I say, "Eight," then pause and add, "I have no idea why."

To show the cake to Hannah, I place it, tentatively, on the floor a few feet from her, and immediately it obsesses her, and she crawls to it so fast that before I can lift it out of reach she puts her hand straight into the candle flames, then pulls it away with a cry. I grab her up quickly and comfort her, apologizing endlessly (and feeling very stupid). Matt says with a laugh, "Burned by her first birthday candles. Let's hope that's not an omen." In a few moments, everything's back to normal.

And our version of "normal," when viewed through properly chilled and narrowed scientific eyes, seems bent on displaying the same aberrations those researchers were looking for in their own first-birthday analyses. Hannah doesn't actively avoid eye contact, but she doesn't seek it out, either, and in fact you have to be wildly entertaining, in baby terms—your face mobile as a clown's, your voice high-pitched, singsong, endlessly excited—to hold her gaze for more than a second or two. People seem to interest her less than things do—the video camera, her party hat, the cake. She never gestures or points to anything around her (in fact, she will *never* do these things, through all her life), and pays no particular attention as we sing the birthday song. She's in a quietly good mood, but gives the impression that she'd feel just as tranquil if left completely alone.

But the thing in the video that strikes me most tellingly, most painfully, as I watch it again from my perch on the edge of the coffee table, is the behavior of Luke, Hannah's sixteen-month-old "first friend" and the video's accidental control subject. He stands wide-eyed through the ceremony and never utters a sound, and indeed what's striking is how timid he is, how he clings

to his mother's leg, with most of his body behind her. He's been to our apartment a dozen times before, and we've even babysat him several times, but still he's leery, and he studies us all—our vocal tones, our facial expressions—as if seeking clues to how safe he is here. Like other babies I knew at the time, his world-view is tentative, careful, ready for panic. And I realize now, as I scan the wavery video, that I noticed that stark difference at the time, but that I must have interpreted it wrongly. I must have thought it a positive—maybe even a superior—thing that Hannah never clung to me that way, and that her approach to the world was always blithe, determined, bold. She was, I must have thought, the Christopher Columbus of babydom.

A few days after re-watching the birthday party, I'm sitting in my living room, typing this, and in the middle of it I look up and ask Henry, who's reading in the chair beside me, "Was Hannah ever afraid of anything?" I hesitate before I ask this, because we don't talk about Hannah much, he and I. There seems to be an unspoken taboo about it, especially when it comes to the hard parts of our life with her. Occasionally I feel all right in mentioning something silly she used to do, or some talent she had, but to ask him about her fears—or, rather, her fearlessness—takes a bit of courage. It seems to me I could so easily drag him down into the slump I myself have fallen into so often—or, no, that's not how it works. His defenses go up too quickly for that to happen. He'd let the subject lapse before it could go that far. But one question is sometimes okay. He can think about it for a second, give a measured answer, and go back to reading his book.

"No," he says now, "I don't think so. She'd scream and have tantrums, but it wasn't that she was afraid. It was—"

"Pain," I say.

"Pain," he agrees. "Stress."

"Something internal, maybe, that we couldn't figure. But not fear, I don't think."

"No." After that I go on remembering, to myself, a dozen examples of Hannah's lifelong fearlessness. All the mad dashes she made for the fountain in the mall. The frequent running up to strangers, leaning her laughing face, forehead to forehead, against theirs. The way she grabbed or straddled our patient dog, or stood balanced and squealing on the high crossbar of her back-

yard swing set, or, upon entering our friends' homes, flew straight as a crow to their refrigerators.

The day at Burger King, when, as we walked past, Hannah grabbed a handful of French fries from a stranger's table—this when she was three, a couple of years before she looked and acted so obviously disabled that most people would know better than to get overly upset by such a thing, when they wouldn't put her behavior down merely to bad parenting. The woman in this case was nonplussed then furious. She stood up from her neon-plastic swivel-chair and harrumphed, "Do you mind?!" with an air of brittle, formal indignation that I found funny, even at the time. Still, I was also mortified, and apologized profusely. The same sort of thing would happen a few years later, this time at a Taco Bell, and this time the stranger simply gave Hannah her burrito, and while Hannah sat down and devoured it, I bought the stranger a new burrito. And when I handed it to the woman, our eyes met, and for one long, real second, we were bonded by her grace, my gratitude.

“I meant to have but modest needs”

Diary entry, January 16, 1989:

Hannah and I are home alone while Henry’s in Butte, Montana, of all places, for a job interview. He’ll probably get the job—an assistant professorship, teaching mostly composition to engineering students. A raise of pay (\$23,000!) and a higher rank, and three classes instead of four—those are the draws. And the disadvantages are the bitter location (I imagine), the crummy little mining school—possibly isolation, not many chances for good friendships with people we can be close to. But it feels kind of neat to me—a big adventure, why not? In this place, we’re cramped and we know every nook. I recently put the lamp at the other end of the couch, and the change was delightful to me, which made me wonder how much I might like a new house, new furniture, a different view.

I’ve lived in Butte for over 25 years now, but even now I still sometimes think of it as “Butte Montana, of all places,” and I don’t think I’m the only one. Look closely and you’ll see it in movies now and then: the would-be rodeo star who has never seen the likes of a town bigger than Butte, Montana; the drifter boyfriend who tries to persuade his skeptical girl that the “city of the future” is Butte, Montana; the rules-are-for-suckers FBI agent who, punished for his hubris, gets reassigned to Butte, Montana. Sociologist Barbara Ehrenreich, who was born here in 1941, has said that in her day Butte was “a bustling, brawling, blue collar mining town,” and this seems true even now. Oh, we may not bustle so much anymore (what’s the hurry, after all?), but we do still brawl on occasion, and most Butte collars remain true-blue. Today, Ehrenreich calls Butte “a sadly under-populated, woefully polluted, EPA superfund site,” which is also true, of course, except that we’re not nearly so sad here as you’d think we surely ought to be. This *is* the “Can-Do City,” after all.

“They sell postcards of the strip mine,” I wrote to a friend, not long after the move. But I was wrong about that, and have since been corrected several times. It’s not a strip mine at all but an open-pit mine—a huge tiered scar just east of town, which its admirers compare, without apparent irony, to the Grand Canyon, though of course it’s more impressive than the Grand Canyon because it’s manmade. At the bottom of the mine lies a serene brown lake, formed by run-off and laced with a thousand poisons, residue from a century of copper mining. In the local

paper, I once read someone claiming, in a tone of wonder, that if all the separate chemicals could be extracted from that lake, they'd be worth millions.

And that's how its citizens tend to think about Butte. They (and to some extent I must mean "we," because after a quarter-century it gets harder to pretend I'm just a visitor here) take pride in every local thing, from the high school sports teams, to the renovated Arby's, to the brand-new turn lane at the corner of Platinum and Montana. But it seems they save their greatest pride for Butte's dilapidation, its gritty history and working-man traditions, the fact that people get drunker here on Saint Patrick's Day than in any other town this side of Dublin. It's a fierce, defensive, survivor's pride, because Butte's people have made it through everything—the hurly-burly mining days, and then all the long years of economic depression once the mines began to close, back in the seventies. In August of 1989, when Henry and Hannah and I first arrived, we were always hearing on the news that Butte was on its way back up. "The city that wouldn't die" was how the town's chief executive once described it. Henry loved that phrase. "Like a horror movie," he said. But, then, he wasn't nearly so happy with the place as I was.

Strange to say, but I liked Butte right away, from the moment I first glimpsed it from the top of the airplane ladder (it would be years before they'd cut the launch ribbon on the fancy new "skyway"), and never stopped liking it, even as I got new information. I liked, and still like, the squalor of it, the stately old mansions built in the mining heyday but now often left empty and decaying, their yards overgrown with dandelions and knapweed. The packs of dogs running free. The old red-brick uptown buildings with hand-painted advertisements from the 1940s still faintly visible on their sides. The way, no matter where you are, you always seem to be on the edge of town, just a stone's throw away from miles of sagebrush and parched, yellow-dirt hills.

We rented our first house sight unseen, over the phone from Virginia. It turned out to be a decrepit little place, with mismatched carpet and mustard-colored walls, and a washer and dryer lined up starkly in the hallway off the living room, jutting out so that you had to sidle crab-like to get to the kitchen. Still, it was a house, and this was the first time I'd ever *had* a washer and dryer.

The place had two bedrooms and was located on the steep hill only a block and a half down from the Montana Tech campus. In the summer, a trolley car—really just an open-air bus—took

visitors on tours of Butte that went right past our house several times a day, and often I would be sitting there on the front step, while Hannah ran through the sprinkler I'd set up in our tiny front yard, and as the tourists gazed out at us, wearing the same glassy-eyed look of tourists everywhere, I suppose, they sometimes waved to Hannah, whom the spouting water had made delightfully giddy, and who looked—quite objectively--darling in her little bathing suit and sunhat. I'd wave back on her behalf.

On many afternoons, that first August, before Henry started his professorship, in those days when we knew hardly a soul in town, we'd take Hannah for a walk up to the college, which consisted then of ten or twelve buildings lined up like tombstones along the crest of the second highest hill in Butte. (The very highest hill has an actual, if not especially exciting, name—"Big Butte"—and is located just north of the college. It's barren except for a huge letter "M" on one side, which lights up every night, and cleverly flashes off and on into a victory "V" on nights when Montana Tech wins a sporting event--or else, as legend has it, when the chancellor gets laid.) We'd walk through the campus to the practice football field on the far side, and there, on the outskirts of town, away from everybody, we'd set Hannah free. She might spend half an hour just toddling back and forth the length of the field, from one goal post to the other, while we'd sit on the hillside watching, always hoping she'd exhaust herself, despite our knowing quite well that this would never happen.

Nevertheless, we could have a pretty nice time up there. Those August days were lovely—clear, dry, sunny, but cool enough for sweaters sometimes. Henry and I would sit there, talking or not, while I idled away the time by running my hand through the thick, well-watered grass, looking for four-leaf clovers. After a few afternoons, this search became my obsession, in fact, if anything done that lazily can be called an obsession. I'd be so intent on looking down, sifting through the clover, and Henry, as usual, would be so lost in his own train of thought that we'd lose track of Hannah, and she'd wander toward the gravel road that bordered the field. Not that there was any traffic out that way this time of year, but the road was the limit we'd set, so one of us would have to lope after her, lead her back to where we were. Then immediately, fearlessly, she'd wander off again—never once hesitating, nor even looking back—and so again we'd go get her, reel her back in like a kite, then loll away the five or six minutes that would pass before she once more reached the road.

Meanwhile, I must have found a dozen four-leaf clovers in the course of just a few days on that hillside. It got to the point where I didn't even save them anymore, and I began to realize, with a soft, minor-league sadness, that it was all a sham--that they weren't so rare and lucky after all.

“We never know we go, when we are going”

Diary entry, November 2, 1989:

Henry and I have been fighting off and on since we got here. In September and October, we talked about divorce. He actually called to reserve a one-way ticket for me and Hannah to Denver [where some of my family lives]. I threw my birthday cake at him in September. He's started drinking again. He's circled ads for apartments in the paper. I try not to shout or cry in front of the kid, but it's hard to help.

And what's it all about? Nothing specific—just this sense that we don't like or trust each other. No intimacy, no sex, no common ground. I have hated him sometimes in the last months, found him utterly unattractive and selfish and tedious. They're horrifying feelings—my whole world crumbling; I never thought, no matter how many fights we had, that I'd ever lose that base of love. But there it is, revulsion. Probably he feels the same about me.

Since the baby this crisis has been coming. He's never gotten used to it, and I've never been able to sanction his ambivalence and selfishness. We're not the family I thought we'd be. He's still the outsider, never knowing which drawer Hannah's pajamas are kept in, what she eats for dinner. He's not comfortable with Hannah, gets nervous when I leave her with him, and as a result I have less freedom than I should, and he never learns her ways, and the situation perpetuates itself.

I've wondered sometimes: If Hannah had been neurologically typical (“neurotypical,” for short, or, in the unimpressed shorthand of autism support groups, simply “NT”), would Henry and I have fought with each other as much as we did in those days?

When I ask him now, Henry says no, that Hannah's disability—though we didn't know she had one at the time—was a huge source of stress. He points to the fact that she never slept through the night, and that I ended up—for over four years, all told—sleeping next to her on a mattress on the floor of her room, nursing her off and on through the night, and sleeping when she slept, in the intervals between. He remembers, too, the way, when I would leave her with him, she'd shriek for the entire time until I came home—and it was “shrieking,” yes, and not just crying.

That's coming back to me now—in a visceral, shuddery way—how her wailing pierced the air when she was upset, and how there seemed to be in her no middle ground between cooing contentment and total agony. Henry remembers how Hannah's all-consuming place in our lives turned him into a workaholic who never wanted to come home, and me into a frowzy, perpetually exhausted *hausfrau* who could only think, talk, and care about Hannah.

I understand his points, but I have my doubts. I think we would have fought anyway. Our marriage was built on marshy ground, and it would be many, many years before we learned even the most rudimentary strategies to shore it up. Our arguments had always been ferocious, and it's not surprising that they remained so, once Hannah arrived. If she had been a 'normal' little girl, I'd probably still have thrown my birthday cake at Henry. The only difference is that Hannah would have noticed.

She was always in her own world, even then. For a lot of every day, at least as I recall it, she was happy, and sometimes she could even entertain herself. She loved stacking blocks and watching them fall; pulling pans out of kitchen cupboards; splashing all the water out of the kiddie tub I'd set up for her on the kitchen floor. She loved opening and closing things—doors, cabinets, drawers, books—and was an absolute sucker for jack-in-the-boxes. She loved listening to music, especially while rocking either with me or in the freestanding, wind-up baby swing she'd known since infancy.

And here I feel compelled to insert a brief but passionate tribute to that baby swing, for it saved my life many times. It was the only thing besides breastfeeding that could put Hannah to sleep, so at nap times I might buckle her into its basket seat, put a rattle in her hand, turn on the vacuum cleaner (or, after the eventual breakdown of several cheap vacuums, a tape recording of a vacuum cleaner, or else a tape her grandpa had made of water pouring from a bathtub faucet), and she might rock for nearly an hour before waking. Meanwhile, during the 16-minute (I timed it) interval between swing windings, I could get the dishes done or even take a sorely needed shower. We took the swing everywhere, both to local friends' houses and on cross-country family visits. I soon became an expert on its assembly/disassembly, and could speedily fit the whole thing into a large suitcase. Hannah rocked in that swing for years beyond the point of growing too big for it—till she was four, maybe, at which point it groaned and creaked beneath her weight, and her feet brushed the floor on the downswing. We knew that, any minute now, the

thing might simply collapse, and one of my many maternal negligences was that I was *utterly* willing to risk that calamity. Nevertheless--god bless that rickety machine—it never broke.

Facts: I've given birth to two children in my life, and one was remarkably hard to raise, and the other--my Becky, born five years after Hannah--was remarkably easy. Thus, my judgment of whether Hannah's early years were atypically difficult is clouded by my almost complete inexperience with typicality. Still, I can think of several events that surely would have gone more smoothly if Hannah hadn't been autistic. Cutting her hair, for instance: it took years for her to learn to tolerate the swishing of scissors as they opened and closed, so I used to wait till she was asleep to give her a haircut, which was, of course, a tricky thing in itself, and the results were always ragged. In later years, whenever the doctors sedated her for an MRI or an EEG, I'd take advantage of her unconsciousness by bringing a scissors to the hospital with me—and a nail clipper too, while I was at it. Once I even asked our family dentist to join the team and, as soon as the sedation took effect, he gave Hannah a quick, deft oral exam.

In the summer of 1990, when Hannah was nearly two years old, a couple of friends, along with my brother Brian, came to Montana for a camping trip to Glacier National Park. We all drove up there—for how blithe I was in those days, to think that way: tra-la-la, let's all go camping! We drove in two cars, and, as I put it in a letter to a friend a week later, our first night

...went quite well, even if Hannah and I got no sleep whatsoever. Then the next day we hiked a trail up to some famously gorgeous waterfall, and we put Hannah on Henry's back, in a backpack-thing meant to carry toddlers, but she kept trying to worm her way out, strangling Henry in the process. Still, we made it to the waterfall, which was indeed gorgeous and loud and torrential—so much so, maybe, that Hannah kept trying to break free of my grasp so she could leap into it. And while I had a firm hold on her, I truly think, the dozen or so other hikers who perched nearby, lunching and gazing, seemed to disagree, and would let out huge, collective gasps of terror every time Hannah made another do-or-die lunge for the falls. Anyway, she and I ended up taking one of the cars and driving home early. (I drove.) Which went okay until maybe the last hour before Butte, when Hannah was suddenly, inconsolably miserable, and there wasn't much I could do besides sing to her and reach back to pat her knee once in a while. Nothing worked, of course, until finally I handed her a mini-muffin from a package on the front

seat, which calmed her down for a little while, if not long. So for about fifty miles or so I was just sort of flinging mini-muffins back there, at irregular intervals, and the car kept swerving and I very nearly ran head-on into an embankment once, but we finally got home, and really the only bad thing about the whole trip is that the back seat of my car is a nightmare of crumbs.

I've spent a lot of time lately re-reading letters I wrote to friends and family in those pre-diagnosis days, and what strikes me is how tirelessly upbeat so many of them are. It's rare that they even describe the problems we were having—as partners or as parents—but when they do, as in the mini-muffin debacle above, there's nearly always a jocular air to them—gallows humor—and any troubles I do mention are almost always placed in past tense. I write countless lines like “That was kind of a hard phase, but she's getting past it now,” or “I think she may be starting to sleep better at night,” or “She's still not really talking, but she jabbars a lot, and I think it's just a matter of time.” Such bouncy optimism is partly just a reflection of the Pollyanna I was back then, in the three years before Hannah's diagnosis (and even after, and even today). And partly it's due to some deeply rooted impulse never to inflict myself on anyone: I've seldom been willing to tell the people in my life just how hard things are, or have been, for me, for us, for her. I haven't often been my life's best witness. I suppose that's one reason I'm writing this book.

“On my volcano grows the grass”

I don’t know that I’ve been telling these early stories right. For one thing, they all seem so *ominous*, don’t they? All filtered through the blueish haze of that “disability” we didn’t even know about till Hannah was nearly three years old. Re-reading now, I can’t help but notice how spooky, how inscrutable my little girl seems, even in my own memory. But that’s not how I felt at the time.

At the time—those first three, pre-diagnosis years—Hannah seemed, if not exactly transparent, at least no less knowable than anyone else in my life. Indeed, I believed—and perhaps it’s even somehow true—that she was the person I knew best, back then, and that I played that part for her too. We were the centers of each other’s tiny worlds—yet so often I can’t remember that anymore. I tend to think, no, no, it was mainly my breast she wanted. Whatever else, who knew? And there’s something true-ish about this, in the sense that Hannah and I lived primitively—like primates, I mean—in those days. The baby gorilla, as she suckles, gazes up at her mother’s eyes. The mother gazes back. In this brief moment, which will somehow last forever, they are mutually enthralled. This is love.

In truth, I never once doubted, during those first years, that Hannah and I were settled—shabbily, cozily--somewhere safe within the big inclusive nest of neurotypicality. All day long, it seemed, we simply stared at each other in wonder. True, I couldn’t always understand or solve her troubles—which I now suppose may have been more intense than those of more run-of-the-mill babies—but I believed I could read her feelings, and she seemed able to read mine. We rocked, sang, cuddled, bathed, nursed, napped, gazed. Our bond seemed deep.

Let me take a breath and say that differently: Our bond *WAS* deep.

I’m very nearly ready to believe that again now. It was only the fury of many hard years, after all, that eroded “was” into “seemed.” It was the click of a moment, really—a few words in a doctor’s office that I’ll get to soon enough—that changed my reckless habit of “of course” into a litany of “I have no idea.” Only one thin second before that awful click, I’d known very well what perhaps it’s high time for me to learn again—that Hannah loved me, for real.

I think that, somewhere deep down, I’d rather believe she didn’t. Throughout the fourteen years she was labelled “autistic,” I tended to see Hannah as mostly oblivious to us all, as living alone

in a world so entrancing, and so magically self-contained, that she required no one and nothing beyond the simplest external necessities. I liked to think—I still more or less believe—that she *preferred* her inherent solitude; that she might well have *chosen* it, had she somehow been offered a choice; and that, to her, other people were often far more trouble than they were worth. With time I learned to feel glad that Hannah never seemed to notice her own disability, much less feel embarrassed or ashamed. Tribalism, with all its trappings and insistences, meant nothing to her. Though bullies might try, they couldn't hurt her, for she simply didn't notice their existence. She might never make a friend, or take pride in an achievement, or fall in love, but at least, I reasoned, she had no idea what she was missing. (Neither did we, I always added quickly. We didn't know what we were missing, either. For however mysterious the workings of Hannah's world remained to us neurotypicals, even we could see it included ecstasies far beyond our NT scope.)

And there was love in her too. (Wasn't there?) And not just for me, but for, oh, so many other people along the way. Evidence from a 1999 teacher's report, under the heading of 'Student's Strengths': "Hannah's strengths are her ability to form special attachments for caregivers and her ability to balance on things." ('And sometimes both at once!' I want to add.)

It's really just a self-centered narrowing of the question that's haunted me from all our ends and beginnings: who was Hannah? For years I've gazed at galaxies of evidence, but doubtfully, absurdly—an astronomer who knows her "telescope" may be only a mirror. But now it's the co-question keeping me stuck: *did* Hannah, *could* Hannah love me? Some part of my heart, you see, doesn't *want* to know the answer. I love Hannah with my life, and by now no longer mind so much the pain that attends that love. Though it's taken years, it seems I'm beginning to consider our time together as a sort of rigorous miracle, a harsh bliss.

But what happens as I sort through the data yet again? What if I catch, again and for sure, the gleam in Hannah's toddler gaze, and interpret it exactly as I did when it first flickered? Because I knew it, knew it, knew it then, as well and as thoughtlessly as I know my own heartbeat: Hannah and I shared an elemental bond. Call it love only if "love" is a word deep enough to contain it. And if I go back to re-remembering this love, in all its savage palpability—can I bear that too? (Ah, but at this point who am I kidding? The answer must always be, "Yes.")

When you lose someone you love, why should it be easier, even if just a little, if you demur (as if humbly!) from recalling that they loved you too? Why should Hannah's loss feel suddenly harder, suddenly *fresh*, now that I'm invaded again by all we were to each other?

In lieu of conclusion, I write a poem:

On days you can't remember

*On days you can't remember who she was,
you disinter the pictures (you don't want to!),
then focus on benign peripheries,
so that the first contritenesses that haunt you
will show themselves banal: 'whatever happened
to that armoire?' 'That dishwasher broke down.'
'I miss the velvet couch.' 'I wish we hadn't
let the thistle overrun the lawn.'*

*Entice your vision toward more pointed hints:
Salute the crib, the changing table. Welcome
a glimpse of diaper bag. Recall its scents
of disinfectant, sour milk, and talcum.*

*You deftly sidestep 'what's she thinking here?'
and 'does she know it's me behind the camera?'—
yet trip on 'why such tangles in her hair?'
and 'did we never change from our pajamas?'*

*Retreat beneath the quilt her grandma made.
Review the popup book, rewind the mobile.
Respin the top, recoil within the bed.
Renurse, resing, resigh, relaugh, rebabble.*

*And, should you need to, build a sturdy house
of quatrain stacked on quatrain. Window-free*

*at last, live lyrically, your mind diffuse—
all squinting rhymes and harmless frippery.*

Go, dear one. Pile words one upon another.

Form thick iambic castles, if you wish.

*You have the right, love—you who were her mother—
to veil what life remains in artifice.*

“I had no cause to be awake”

Somewhere around the time Hannah was fourteen months old, I started to think that her everyday moods might be stable enough—and, just as vital, scrutable enough—for me to leave her with someone for a morning now and then, so that I could go back, for a little while, to being a writer. A friend recommended a small day-care facility a mile or so away, run out of the home by a good-natured, casual-minded mother in her late thirties. And so it was that, in a state of fear and an even heavier cloud of guilt, I brought Hannah to Kathy’s house, where she would stay for two days every week, three hours each day, all through the period of her second and third years.

Parenthetically, perhaps: Some five or six years after that, when I brought my younger daughter, Becky, to her first morning at another day-care, and she was hanging on me, begging me to stay, wailing if I backed so much as an inch toward the exit, I’d suddenly realize, “So *this* is what it’s supposed to be like.” From an email to my sister in August, 1995:

Becky’s been to day-care twice, but I’ve always stayed right beside her (her idea).

Tomorrow the plan is to leave her there a couple of hours—wish me luck. I’m not much at being firm about such things, and she’s so clingy and shy. Still, yesterday she really started exploring the place, and even socialized in her toddlery way (so cute, that). I filled out the required form, and when it asked if my child had any special handicaps, can you imagine, I got tears in my eyes when I wrote the word “none” in the blank. What luxury it is to see her around other kids, acting like other kids, making readable, human sense not only to me but to people she’s only just met.

It would be another year before, at least by my soft-hearted standards, Becky was ready for daycare.

But with Hannah it had been easy. True, I’d been reluctant to leave her. (And when I got home, in my depthless maternal guilt, I didn’t waste a moment, nor allowed myself a hint of writers’ block, but went straight to work, so that by the end of nine months’ time, I’d written the first draft of my first novel.) But the hardest part of day-care, I think, was in seeing *Hannah* leave *me*. It’s what she did, you see—I brought her in through Kathy’s kitchen door and she toddled off immediately to the living room, where various toys lay (forever) scattered. As always, she didn’t

look back, and I was able to make a quick, unremarkable exit. Later, I remember telling people how very “brave” Hannah was.

Why didn’t we know? It’s such a humbling thing, such a comeuppance—one of so many comeuppances through which Hannah teased and tamed me, over the years. I thought I was such a sharp cookie, you see, and, especially where my daughter was concerned, I thought I knew, if not everything, then at least more than anyone else. Yes, Hannah was “delayed” in some ways—though I didn’t really notice most of them. Only in retrospect do I understand that, though she often made eye contact, it was usually more of a maniacal stare-down than a comprehensible sign of engagement. She reveled in the usual baby games (peek-a-boo, this little piggy, blubbery kisses on her belly), but seldom in play that required reciprocation. (You could roll a ball to her, but she wouldn’t roll it back.) Her interest in make-believe was nil: her fascination with a ragdoll might be limited to, say, an obsession with removing its button eyes; and though she liked to spin the wheels of a toy car, she never pretended to drive one. She wouldn’t play with other children, and, indeed, showed no interest in them whatsoever, but only in adults, and mainly in what adults might do for her.

Moreover, at nearly three years old, she still didn’t speak—not coherently, anyway. That was the big thing. That, we noticed. Yet even there I wasn’t worried. After all, hadn’t we heard (like a broken record, after a while) that Einstein didn’t speak till he was four? Plus Hannah jabbered endlessly, and in amongst the flow of gibberish, I was sure I could make out a few meaningful words. Witness this letter from May of 1991, when Hannah was nearly three years old:

Yesterday we had a sort of dialogue. “Lie down,” she said. (Her favorite thing is for me to come lie in her bedroom with her, where she can show me books, play with my hair, and generally jump all over me. Every day I spend, literally, hours on that bed with her, she brings in dolls and toys, and it’s an easy relaxing time, especially since I myself am allowed to bring books and magazines and, now and again, to read them.) “No,” I said. “I’d like to watch TV.” And she looked at the TV, looked at me, and said, “Lie down.” “No, I’d like to watch TV,” I said. She looked at the TV, again at me, and then she laughed. Her first acquiescence.

In retrospect, I still believe that Hannah was actually saying, “Lie down” (though the syllables themselves probably sounded something like “die dah”). She’d also picked up on my Winnie-the-Pooh-inspired phrase for nursing, “a little something” (as in, “Is it time for a little something?”) and could say—and did, sometimes urgently, many times a day—“sum pea,” which meant, without a doubt, that she wanted to nurse. Most heartening of all, for some reason, was the fact that she’d learned to tell us what animals said. “What does the cow say?” “Moo,” etc., all the way up to the polysyllabic rooster: “Oo-ah-oo-oo.”

Nobody told us to worry, not even our pediatrician. Nobody—neither friends nor family—said much of anything about Hannah’s delays, even though, years after the diagnosis, several admitted they’d had their suspicions. I remember a couple of exceptional moments: once, when Hannah was two-and-a-half, one of my sisters said, in a tone of extraordinary reluctance, that maybe Hannah would talk more if I didn’t “baby her so much.” She pointed out, especially, the way I warned Hannah against getting into things: my nonchalant, singsong phrase, “Not for babies!” And it was true, I did chant that phrase a lot (I can hear its cadence in my head as I type it out here), because Hannah was into *everything* then, and would continue, all her life, to be the personification of entropy. On the family visit that prompted my sister’s concern, Hannah had already broken two of my mother’s floor lamps and had nearly pulled down the Christmas tree.

Still, I wasn’t overly concerned.

Honestly, you’d have had to hit us over the head with a rock to get our attention in those days, and even that might not have worked. One day I arrived at the day-care to find Kathy the caregiver in a state of mild distress. “I’ve punished the boys,” were her first words to me, and she really couldn’t imagine why they’d done it, it wasn’t like them at all... It finally came out that while Hannah, two-and-a-half by then, was sitting alone in Kathy’s back yard, sifting through dirt and singing her usual formless song, a trio of slightly older boys decided it might be fun to throw pebbles at her back, trying, I suppose, to elicit a reaction of some kind. After a minute or two, Kathy had noticed and put a stop to it. Hannah herself hadn’t responded at all, hadn’t even turned to look, and now, at the time I was coming to get her, she seemed as disinterested and self-contained as ever. A few weeks later Kathy mentioned—no doubt pointedly, it seemed to me only much, much later—that her daughter was writing a report on autism for a high school

assignment, and was using Hannah as her chief “test subject.” My outward reaction was a mere, unruffled, “Huh.” Inwardly, I rolled my eyes at the silliness of such an assumption.

Of course we knew that Hannah was “behind schedule”; we just didn’t worry much about it. We figured she’d catch up eventually. Nonetheless, in May of 1991, two months before her third birthday, I brought her in for a screening at the local Headstart program, where the teachers who tried to test her told me no more than I already knew—that Hannah was “delayed.” As a follow-up, I took Hannah to meet with our pediatrician at the time, Dr. Knutsen, about whom I remember not a single thing beyond the fact that he thought everything was probably just fine, but recommended we visit a pediatric neurologist in Helena, just to make sure.

“Will there really be a morning?”

Something—a letter to himself, or maybe to no one. Three scribbled notebook pages, front and back, that my husband Henry wrote on May 20, 1991:

It's 4:30 in the morning, and we just found out yesterday, after taking Hannah to see two experts in child developmental problems—a speech pathologist [actually, a pediatric neurologist] and a speech therapist—I believe those were their titles—that she has, according to both of them, a “mild case of autism.” I don't know why I'm writing this, except that at the moment I don't know what else to do. I don't expect it to help, at least not in any fundamental way. The only thing that would help in that way is to find out that she'd been misdiagnosed, or, at least, that there was real hope that she could be “cured” and lead a normal life.

I slept for about four hours, and had an awful nightmare. I dreamt that I had a terminal disease; it didn't seem to be an actual disease, but it progressively deprived you of memory, and killed you pretty quickly...and then at a certain point [in the dream] I stood up, and looked at myself in the mirror, and for a face all I had was a skull... Anyway, I guess the dream expresses basically how I feel. It's not like, exactly, that I have a fatal illness and just discovered that, but it's the closest thing to that that I can imagine. One thing that the speech therapist said was that learning this feels like a death, like someone we love has died—that, I guess, has been a recurrent way families who've experienced this have described it. And now we need to learn how to love this new person, this Hannah with autism. We haven't reached that second stage yet, of course—I dearly hope we're able to, eventually. But that sense of someone we love dying, that's exactly how it feels. I look at Hannah, and I think of all the hopes and dreams and plans we had for her, all the things I expected to experience and share with her, just as any normal parent and child do, and now I don't know if any of that will happen at all. I also feel so sad for her, to be trapped inside this. Nancy said, and it struck home with me, that from now on nothing she does, no behavior, will seem right, or comfort us. If she's happy—rocking to music or jumping around—then we'll assume she's doing what the speech therapist called “self-stimulating,” sort of “trancing out” in her own little world. And if she's

unhappy, crying, then she's frustrated, trying to express something to us through the prism of her autism.

This news has taken both Nancy and me almost completely by surprise. I really hadn't been thinking much about the appointment; I was very busy completing the semester, and I've been looking forward immensely to being out of the classroom for three months, writing my criticism and especially my novel-in-progress. We knew Hannah was behind in her speech, but we didn't take it as anything serious. Nancy said that she was going mostly for other people, so they'd stop asking about it, or not asking but clearly thinking about it—Kathy, who runs the day-care center Hannah goes to, my folks, my friend Mike, who's in the psychiatric profession. We had to drive up to Helena, since there's no speech therapist in Butte. Sitting in the room of the speech pathologist (if that's the term) waiting for her, we made jokes—telling Hannah she'd better talk so the doctor wouldn't think we'd raised a “moron,” that kind of thing. On the drive up, we'd talked about our constant sense of indignation at the world, its stupidity and injustice—in politics or academia or just the behavior of people we know, all of which seems incredibly remote and trivial to me now, the kind of vague existential problems I wish I had instead of facing this.

It's now 5:37. I'm getting a little sleepy. I really should try to get some rest; I've only had about four hours of sleep.

“I lost a world the other day”

Before the appointment, we stopped at the Helena mall. I bought two CD's: Rod Stewart's *Sing It Again, Rod* and Anne Murray's *Greatest Hits*. There was still free time after that, so we took Hannah to a park, where she spent maybe half an hour on the swings before we drove to the doctor's office.

I'll keep her anonymous, I guess. I'll call her Doctor G, because there are things I may say about her that she might not like, things that may even be unfair. After all these years, I still don't know what to think of the way she handled things. It used to be the first in my repertoire of grief anecdotes: the way she spent some fifteen minutes observing Hannah, in her office, while we, bemused, observed them both. And then she turned to us and said these exact words: "I think I can put your minds at ease. I think your daughter is autistic."

It seems to me now that she said this in a German accent. I ask Henry, and he says no. Her name was German, but she herself wasn't, he says. I remember that she was maybe fifteen years older than we were and had short, reddish hair, and that she looked owlsh behind her big-framed glasses. I remember that a few years later she ran for the state legislature, but I don't remember if she won. Henry would almost certainly know the answer to that, but it's probably not worth my asking him. Instead, I ask Henry if there's anything else he recalls about that day with Dr. G, and when he hesitates I ask him whether he minds talking about this, and, after a moment's thought, he says no. He thinks again, and says he remembers that when we asked her if she might somehow be mistaken, Dr. G replied, "I'm very comfortable with my diagnosis."

It occurs to me that both of us may be misremembering Dr. G. For one thing, her official, three-page report of the appointment says that her evaluation, which I recall as lasting maybe twenty minutes or so, actually took an hour and a half. And though Dr. G's "affect" (as she herself might refer to it) was cool, I see that her interactions with Hannah were much more focused and intimate than I remember. Her words in the report:

[Hannah] wanders from one activity to another when left to her own devices, does not show any representational play, even when invited to do so. She does respond to her name by immediately looking to one's voice and spontaneously picked up a telephone but I could never get her to carry on any kind of conversational interaction relative to that. I

could also not obtain any kind of interaction relative to looking at pictures or toys. She seemed exceedingly interested in exploring objects, and in particular people (namely me) by touch. She would come close to my face, looking directly in my eyes, reach her hands to feel my face, and did this in a very gentle exploratory fashion. This was repeated on several occasions.

Toward the end of her report, Dr. G writes, “This is obviously a difficult encounter for the parents today, as to use terms like autism is very frightening.” So in fact she *did* notice us, shrinking in our chairs, barely able to move or speak. I’m thinking now that her inability or unwillingness to acknowledge our pain may have been an occupational hazard—the self-preserving distance that must come from a long career of having to deliver such terrible news to so many and such clueless people. Maybe this also answers another question I wondered about years later: why Dr. G chose to call Hannah’s case “mild,” when I couldn’t help but think she must have doubted that? But maybe she didn’t have doubts. After all, as she writes in her report, Hannah “is affectionate towards and clearly responsive towards her parents.” That attachment, along with Hannah’s interest in other people, as compared with the aloofness shown by so many autistic children, gave hope to a *lot* of experts, in those early years.

At any rate, Theresa, the speech therapist, was more visibly caring. We took Hannah to her room immediately after seeing Dr. G. Theresa seemed to know from our muteness and vacant expressions that our world had just dissolved. She played with Hannah for a little while, but mostly she talked to us, told us how normal it was to feel so stunned, told us it was like a death, told us to try not to draw any conclusions just yet, helped us make follow-up appointments with her and Dr. G. Her own official report of the visit, while rigorous, ended on an upbeat note:

Positive prognostic signs include:

Hannah’s demonstrated ability to respond to and use words. Her ability to engage in vocal imitation games. Her pairing of vocalizations with her requests.

Her parents’ skills and interests in working with her.

That last point was the sort of thing we’d hear often in the years that followed. It was a double-edged compliment. We were educated, imaginative, perspicacious people, everyone assured us,

who would certainly be able to give Hannah a lifetime of the very best care and training available. Just a few weeks after the diagnosis, I remember a friend telling me, in a hopeful, gushing voice, that if anyone had to have an autistic child, it was so good that it was Henry and I, because we were so dedicated, so strong, and so very, very wise.

The drive home from Helena was largely silent but for Hannah's singsong gibberish, her giggling and the bump-bump of her rocking in her car-seat. When it was over, when we retreated inside our ramshackle house on the hill, one of the first things I did was put the Anne Murray CD on the stereo, set on infinite repeat. I don't know why I did this—just thoughtless habit, I suppose—but it was a dumb thing to do, because it meant that for the next few hours, as I lay on my bed and stared out at nothing and finally cried and then kept crying, unable to stop, those songs were playing over and over. "Snowbird." "Broken-Hearted Me." "Danny's Song." "Daydream Believer." "You Needed Me." Sometimes, in the many years since then, when I'm shopping for groceries, an Anne Murray song will come up on the supermarket's soundtrack, and it used to be that I'd have to leave right then—abandon my cartful, mid-aisle. But after a few years I got past that response, and came to tolerate those "greatest hits" with only a flinch or a sharp intake of breath. Nonetheless, though that Anne Murray CD still sits on an alphabetized shelf on our dusty front porch, I doubt I'll ever play it again.

I don't know where Henry was, though I knew he was in the house somewhere. Hannah, now and then, would toddle into the bedroom, laughing—she was happy that day, I remember quite clearly—and sometimes she would climb onto the bed for "a little something," and then after ten minutes or so she'd wander off again. She took no notice of my crying, and I would watch her as she toddled away and think, "Who is she? What is she thinking?" After another hour or two of such questions, it occurred to me to add, "Does she love me? Does she know how to love anyone?" But mostly the thought was simply, "Who is she? Who has she been, all along?"

“How dare the robins sing”

Diary entry, July 10, 1991:

We got the news about Hannah, that she’s “mildly autistic,” a month and a half ago. I’ve been reeling ever since. I’ve been deep in grief and worry. There have been times when I’ve thought about suicide, and realized that if I killed myself I’d have to take Hannah along too, because I couldn’t leave her abandoned, and I couldn’t burden Henry with the lifetime of care she needed.

Things are better than that now, I guess. But it’s a long way before “normal,” if normal ever comes. Henry and I have started therapy to help us connect with each other—grief is a tough thing to keep sharing between just the two of us. We feel isolated from other people—who don’t want to hear, who say the wrong things, who aren’t around—and sometimes we’re isolated from each other too. But not always. We’re handling this better than we would have a year or two ago. I think the marriage will survive.

Hannah is happy. This is the lucky thing, the main thing, the thing I’m most scared of losing. She has moods of anger, frustration when she doesn’t get her way or can’t make clear what she wants, but generally she’s happy.

This is my little girl, my baby. At night I hold her as she goes to sleep, and I feel helpless. I’m not past the feeling of shock, of why her. Why us. I’m not past the grief, the longing for the child I thought I had, the deep mourning. But maybe the worst thing now is the fear. Who will she become, how full can her life be? How much of it depends on me? What if I make bad decisions? What if I’m too lazy or exhausted to work with her enough?

You need to understand: in those days—some 25 years ago—autism wasn’t the household word, and certainly not the “epidemic” it seems to be today. No cover stories in Newsweek, no telethons, no celebrity spokespeople, no panics over power lines or food allergies or vaccinations, no overflow in special education classrooms. All I myself knew about autism was what I’d seen the year before in the movie *Rain Man*—a pretty good movie that wasn’t the slightest bit of help to me now.

When finally, the day after the diagnosis, I roused myself to look for resources, all I could find was a massive old medical encyclopedia at the Montana Tech library. It said that autism was a “neurological syndrome” that affected “one out of 150,000 children.” Four-fifths of autistic children were boys, though autistic girls tended to be more severely afflicted. About 70% of children with autism had some degree of mental retardation. About half of them would never learn to speak. Some 20 to 40% would develop seizures before reaching adolescence. I pored over these “statistics,” along with others I dug up in those early days (for a long time I had them all memorized), trying to interpret them in some way that might make them useful to me. But I had no way of telling what they might mean for Hannah, or if they meant anything at all. What good were they, then? The world of statistics and percentages is so much harsher, starker, than the world with a human face. And yet for many weeks they were all I had—these disjointed “facts” from an antiquated medical book, and the movie *Rain Man*.

There was no internet back then—at least not in a form I myself was able to use. But somehow, in the course of that summer, I was able to get hold of a book called *Children with Autism*, edited by Michael D. Powers. First published in 1989, it very quickly became my lifeline, my comfort, my “owner’s manual.” Over the next few years, in fact, I bought several copies, and kept giving them away like Bibles to other parents I’d meet, other parents—and, once, a grandmother—newly hurled into the maelstrom of autism. Written in straightforward language and dealing with practical life, Powers’ book gave me an overview of autism that, without whitewashing the truth, didn’t terrify me the way the medical book had. Particularly helpful to me in the early days was its empathetic opening chapter about the initial shock and grief of the diagnosis. That chapter, like the rest, ended with a series of what it called “Parent Statements”: quotations from flesh-and-blood parents who were facing what I was facing, and who often expressed the exact same fears, hopes, bewilderment that I felt myself. These short, varied anecdotes I read with a special voracity, unaware before now that I’d been starving for exactly this sort of personal story, yearning to know I wasn’t alone.

I read *Children with Autism* with the same fervor and sense of emotional release with which, fourteen years later, I would devour memoirs about the deaths of loved ones—Joan Didion’s *The Year of Magical Thinking* and *Blue Nights*, C.S. Lewis’ *A Grief Observed*, Donald Hall’s *The Best Day the Worst Day*, Elizabeth McCracken’s *An Exact Replica of a Figment of My*

Imagination. (It became a sort of family joke: if you want to get Mom something special for Christmas, buy her a book with the word “grief” on the cover.) Which is why it felt so odd to look up Powers’ book on Amazon recently, and to feel the anguish behind several, more recent customer reviews: “A depressing, horrible book— read only after you’ve given up.” “It leaves the reader with very little hope.” “A dangerous and awful book. Stay away!” “A poorly written, out-of-date book which would be devastating to any parent of a child recently diagnosed with autism. It presents a picture of despair and hopelessness which isn’t even accurate. Copies should not only not be bought, they should be destroyed.” “Don’t read it until your heart is already broken.”

It’s that last quote above that I find most fathomable. It seems exactly right, and encapsulates what I think may be my only real advice for new parents: before you read any book on autism (even the hundreds of life-defying “miracle cures” and shrewdly upbeat “how-to” manuals that have proliferated in the last decade or two), be sure you’re ready for the trip. No matter that your hopes may seem the abnegation of your fears: breathe them both together, in and out, like air. And yes, your heart will leap, and yes, your heart will break. And yes, you need to allow these things to happen, if only because they’re going to, whether you want them to or not.

We called our parents to tell them of the diagnosis; we wrote letters to other family members and friends. Their general reaction, as I write in my diary a month later, was to

jump in with their own ideas—and mostly what they say is they don’t believe it. She’s too outgoing, they say, too cuddly. We’re overreacting. A Montana doctor can’t possibly know what she’s talking about. They can’t stand seeing us suffer so they tell us not to.

That summer we flew to New York City as we always did, to visit Henry’s parents and other friends and family, and while we were there, we scheduled appointments at two hospitals known for their specialization in developmental disorders. The first was St. Luke’s-Roosevelt Hospital in Manhattan, where two or three eager young technicians spent an hour or so playing with Hannah in an effort to determine her strengths and weaknesses. They didn’t get much information of the sort they could record on their standardized forms. She didn’t speak for them, not even to tell them what the cow says, and she paid no attention to instructions they gave her—

to complete a four-piece wooden puzzle, to stack blocks, to draw with a crayon—and meanwhile she made short work of their tidy testing room, with all its colorful, multi-part games and toys.

The moment of the session I remember most vividly is when a technician asked Hannah to point at objects in a picture book. I'd been relatively silent during much of the testing to that point, letting them try to work with Hannah in ways she wasn't used to, in ways that I doubted had much chance of bringing out what she knew how to do. I was quiet because I wanted to see—I thought I might learn some new way in, some lucrative method I'd never tried. I thought, even assumed, that St. Luke's-Roosevelt would know many things I didn't. But when they asked her to point at the pictures, and of course she wouldn't do it, and they were about to place another zero on her testing chart, I couldn't help but step in, just a little.

“Try it like this,” I said. “Hannah, can you kiss the car?” And without hesitation Hannah bent and kissed the picture of the car. “Can you kiss the dog?” And she kissed the dog. And so on, with every picture in the book. I looked up at the technicians with a fleeting sense of triumph. And I don't know if they were impressed or not. I don't know what they wrote on their clipboards—but by that point I just wanted them to know that it was *in there*, the knowledge they sought. It was in Hannah's head all the while, despite how nearly impossible it might be to bring out into the light.

In the end, the staff at St. Luke's-Roosevelt labeled Hannah with the term PDD—pervasive developmental disorder—and let it go at that. It was a sort of catchall diagnosis, I learned later, that covered a lot of autistic-like symptoms without actually using the word “autism.” The doctor we saw next, Isabelle Rapin, of the Albert Einstein College of Medicine, in the Bronx, didn't approve of “PDD”—she thought the term was imprecise, a way of hedging one's bets, a way to avoid looking autism square in the face. Dr. Rapin is an internationally known expert in the field of child development. She's written books, done cutting-edge research. She was quoted and cited in various articles I'd already read. If it weren't for Dr. G—who'd worked with Dr. Rapin years before and knew her pretty well, I guess—we might not have been able to get an appointment with her.

She was a tiny, frail-looking, white-haired woman, and she was sweet with Hannah, letting their visit together flow freely, with Hannah moving from one activity to the next, not focusing on any

one thing for very long. At one point Dr. Rapin actually got Hannah to line up a few blocks on a table, to form a “train,” as she called it, which Henry and I found as wondrous as a magic trick. Hannah liked Dr. Rapin, and jabbered in her presence, and at one point rushed headlong toward her to give her one of her trademark, close-up grins. And to her credit Dr. Rapin didn’t flinch—she seemed a preternaturally calm woman. You got the feeling she’d seen everything before, maybe even atrocities. (Years later I seemed to remember a blue-ish Holocaust tattoo on her forearm, but when I did a bit of research I realized I must have stolen the detail from a dream—Dr. Rapin grew up in Switzerland and had had little contact with the War at all.)

“I think it’s a mild case,” she told us, in her old-world-grandmother accent. “She may not say many words now, but as she grows older you may find that she talks too much. She’ll be quite a little chatterbox.”

I’ve always remembered that word, “chatterbox.” Dr. Rapin made clear that it wouldn’t necessarily be a good thing—that a lot of Hannah’s chattering would be echolalic (parroting the words of other people), or that she might get obsessed with one subject and natter on about it in an endless, irritating way. But all I could think was, wouldn’t that be wonderful—if Hannah got obsessed with something, if she took more than just a momentary interest in anything, anything at all, and if she actually *talked* about it, if she coherently, intentionally, even eagerly, *talked*?

"I shall know why, when time is over"

For years after Hannah's diagnosis, I studied my pregnancy and labor with her "like a detective going over a crime scene"—or so I used to describe my obsession, when first scribbling thoughts for this book. But "a crime scene"—how tone-deaf that metaphor seems to me now. For one thing, every crime needs a criminal, and who could be "to blame" for Hannah's troubles? Even the case I'll make for my own guilt, however damning in its details, would never hold up in a legal court. Nor even in a moral court, maybe—that jury of my veteran peers, all those parents forced off sunny interstates to take winding, bumpy detours through the dark. At any rate, I don't seem to be looking for forgiveness anymore—I discover this as I type it right now. All I seem to want these days is to serve as witness for this true story.

So, no. Not a crime. An accident, then. An "act of God." No one to blame, and—assuming wisdom will ever emerge from all this—not even anything "wrong" to begin with. How, after all, can we judge the paths we're on, except to say they're interesting? If randomness creates the game, it can't, by definition, "break the rules."

But I couldn't have looked at things that way back then. (I'm only just glimpsing them now.) Instead I spent years poring over the "evidence." Surrendering the longing for reasons is a recent, fragile practice for me. Still, I have, for now, let go of "why"—not in a moment's choice, but slowly, via years of listening, lonesome, to its unrequited echo.

Still, for half my adult life I kept a long list in my head: all the choices I might have made or unmade. All the actions and non-actions that, if only they'd been done or not done, Hannah would surely have turned out "all right."

First off, there was the conception itself, which, according to my meticulous calculations, happened on the wrong night. I'd been monitoring my ovulation patterns for three months by then. Every morning on waking, I reached (slowly, so as not to race my sluggish blood) for my bedside thermometer, in order to check my basal body temperature—"basal" because it's the day's starting point, the body's lowest temperature after the chill of sleep. The thermometer was accurate to a tenth of a degree; each day's temperature became a graphable dot on my "fertility chart," on which I also scribbled brief notes about the ever-varying texture and consistency of my cervical mucus. The results—so tangible, so revealing—not only fascinated but soothed me. I

felt like a scientist discovering, dot by dot, the secrets of life itself. I felt like Marie Curie. I felt in control.

So I knew what this cycle's optimal day would be—October 11, as I still recall with fierce clarity even as more openly dramatic memories grow softer. It fell on a Sunday. But a friend of mine from Colorado happened to be visiting Washington D.C. around that time, and I'd made plans to drive up there from Blacksburg on Friday, to stay with her for the weekend. Even so, Henry and I would still have had Sunday night to partake in the sacred miracle of procreation (as we didn't call it), immediately after which I'd have turned around on the bed, placed a pillow beneath my hips, and, for half an hour, lay with my legs elevated, my feet upon the wall.

But I made the mistake of taking the scenic route home from D.C. that day—so many friends having sung the beauty of the Blue Ridge Parkway in the fall—which meant I got home a couple of hours later than I might have otherwise. It was nearly midnight by the time I staggered in, and I had to teach in the morning. I was too tired for miracles.

So Hannah was conceived on Monday, October 12, 1987, at a moment when the egg I'd produced was several hours past its optimal moment of rosy-cheeked freshness. The sperm was different too, of course. And for all I know—for all anyone on earth will ever know—one or the other or both made all the difference.

Or it might have been the seventy-plus pounds of weight I gained by adhering strictly to the "Bradley Method" pregnancy diet. ("Commandment one: Thou Shalt Not Let Thy Stomach Go Empty.") There was also the glass of spiked punch I drank at a Halloween party, two weeks before I knew I was pregnant. And the three sips of Mountain Dew I took three weeks later, before somebody at the dinner table reminded me that Mountain Dew was loaded with caffeine. And the fact that, though my water broke at one a.m. on the day of the birth, the hospital nurse told me to wait till office hours before calling the doctor, so I spent the interim sitting up, alone at the kitchen table, playing Scrabble against myself, when, it turned out, had the doctor known, he'd have advised me to lie down all that time, because I was "carrying high" and without the amniotic fluid to serve as a cushion, the baby's head might be sinking down to crush the umbilical cord, cutting off oxygen.

Then, too, there's this, as I wrote in an email to a friend, some ten years after:

I used to think—I still think sometimes—that it might have been the rough birth. I had to push for so, so long, and the doctor suggested a C-section, but I was so determined to have the baby naturally. You know how we were in those days. And then they had to use suction and forceps, and Hannah came out so bruised, and then she got jaundice. Well, for a while I thought that was maybe the beginning of it all.

And then, it's funny, I was corresponding with this woman I'd met on-line—they've got support groups all over the Net, you know, all of them simply overrun by these amazing Super-Moms who devote their lives to finding the Cure, while meanwhile I'm just trying to figure out how to put the wrecked videotapes back together. I mean, really, these moms, they're like tigers. Tigresses. They'll do anything, challenge every authority, pursue whatever far-out treatment is being touted at the moment, go back to school and become research scientists themselves. In the based-on-a-true-story movie versions, they're played by Meryl Streep. Occasionally Susan Sarandon.

So anyway, I was writing to this woman, this mother with an autistic son, and I told her how haunted I was, thinking if I'd just let them go ahead with the C-section, Hannah might be normal today. And she wrote back to tell me that she herself had gotten a C-section, and now she was haunted by the idea that she should have insisted on a natural birth.

Her jaundice kept Hannah an extra week in the hospital, mostly in an isolated crib in the nursery, blindfolded and naked under hot bright bilirubin lights. The hospital let me stay the whole week too, in my hospital room, so that I could nurse her, I guess, or because they felt sorry for me, or because my insurance covered it. And they all did their best—almost everybody does their best most of the time, I've led myself to think, though I'm seldom keen to test the theory. But they wouldn't let me hold her very often, and many times I was forced to watch my baby girl, wriggling and often shrieking, through the nursery window, sometimes through a gap in closed venetian blinds.

One day I came up to the window and there was a little boy there already, looking through that gap himself. I knelt down beside him so that I could see too.

“That baby sure is cryin’,” he said to me, in a soft, farm-boy voice, in a tone of unadorned awe.
“Just howlin’ the whole time.”

I looked. “That’s my baby,” I whispered back to him.

He was still for a second. “Oh,” he said finally. “Oh. Well. He’s okay. He ain’t been cryin’ that long.”

“One need not be a chamber to be haunted”

Diary excerpt, July 19, 1991:

We live in Butte Montana, and I was fine with that before. Now I hate it desperately because it can't do right by my baby. If we were somewhere else there'd be programs. Now even the speech therapist is in Helena, an hour away.

Henry began to apply for college teaching jobs in other states—in urban areas where the public school systems would surely be more sophisticated than what we could find here in Butte. He focused especially on New York and Colorado, since we had family in those places. But though he received several sympathetic rejection letters, no one was hiring, and even if they had been, they would hardly have done it for such merely humanitarian reasons. Meanwhile, I spent my time worrying about the special education pre-school that Hannah was scheduled to enter in the fall.

I'm so afraid it'll just be a place to stagnate [I write in my diary], “and I'm afraid I'll have to push and push to get the teachers to do right by her, and that even then things might not go well, that it might just be impossible, that the teachers are undertrained and overworked and the whole system isn't good.”

I'd never felt so powerless in my life before. I'd always believed that I was basically free, that nothing I did and nowhere I went ever had to be a permanent choice. For one thing, I'd always figured that eventually, after my meanders into Virginia, Montana, and probably other odd places along the way, I'd end up back in Colorado, surrounded by my large family, who had done their own meandering over the years but, for the most part, had eventually moved back home.

Now I was desperate for a way out of Butte. I talked to Henry about the possibility of widening his job search beyond academia, but it scared him even to think about that. We both knew—or anyway, we assumed—that he wasn't suited for another profession, and sometimes, I confess, I hated him for that, and for generally not being able to save us:

I know it's not fair [I write in the diary]. He's doing a lot for all of us, he's working hard, not letting his misery paralyze him the way mine often does to me, not running away. But we hate each other sometimes for not rushing in, doing more, saving the day. We hate

each other for feeling so bad that sometimes we can't cope and have to ask each other for rescue because there's no one else around to rescue us or even to spell us for an hour or two or even to listen.

Henry's parents had been wonderful during our trip to New York. They'd babysat Hannah every day, taking her to parks and playgrounds, indoor play areas at fast food restaurants, the swing set in their next-door neighbor's yard. Meanwhile Henry and I went out with friends, or just with each other. We rambled along the streets of Manhattan—taking in museums, movies, delicious meals at exotic restaurants—in almost the same carefree way we'd known during our childless years. We could almost forget, for a while, about the worry hanging over us. And when we needed to feel sad, we had time and space to feel it properly. Coming back from that trip had been hard.

In those early post-diagnostic days, though we had friends in Butte, there was no one here that either of us felt truly close to. I used to call my mother in Colorado sometimes, and I must have spent a lot of the conversation looking for whatever comfort I might find in sharing my grief with her. For the first few calls, I believe she stood up to the thing pretty well, and listened sympathetically. But eventually she asked me to stop calling so much, because she simply couldn't "handle it anymore." It shocked me to hear her say this, for I had an absurd, iconic vision of motherhood in those days: that a mother could and would bear anything for the sake of her child. Since then, of course, I've learned so many humbling lessons about my own maternal limitations that I've long since stopped judging my mother. It must certainly be true that she was doing the best she could, just like the rest of us.

I found myself not wanting to bring Hannah to parks and playgrounds anymore, not wanting to witness the contrast between her and the other kids. Sometimes I'd take her, instead, to the local cemetery, and let her gambol among the graves. That sounds macabre, I guess, and maybe it was, because I did take some odd, small comfort in walking among the tombstones, and felt especially drawn to the oldest stones and crosses, which dated back to the 1800s, and to the ones clustered together—whole families buried side by side, sometimes with a stone yet uncarved, reserved for a relative who would join them soon enough.

I was trying to take it in, I think—trying to understand the essential inseparability of joy and grief, life and death, and all the lessons in ephemerality that for all my life I'd managed not to learn before. I'd study the graves, then Hannah, then myself, then the cemetery trees and the clear blue sky, and wonder at the juxtaposition, as well as the transience, of all these things, and there was nothing maudlin about it at all, but instead it felt like the only way toward peace, toward surrender, if only I could take it all in at once, without looking away.

“Hope is the thing with feathers”

Among Avis’s—Henry’s mother’s—first responses to the news of Hannah’s autism was to send me the book she’d just finished reading, a book that, she said, had strongly reminded her of Hannah, even before the diagnosis. It was Annabel Stehli’s *The Sound of a Miracle: The Inspiring True Story of a Mother's Fight to Free Her Child from Autism*, and it was the first of dozens of “miracle” books that I’d end up being given—by a concerned relative, a friend, or a social services consultant—over the years that followed. It’s partly a book about grief and struggle, but it finishes on a note of pure magical joy, as, after many years of misery, the author’s daughter is cured of her autism by a few weeks of a treatment called “auditory integration therapy.”

Other miracle books I read, as time passed, cured their subjects in other ways—some by a dramatic change in diet, some by megavitamin supplements, some by facilitated communication devices, some by chelation therapy to eliminate heavy metals from their systems, some by the use of hyperbaric chambers, some by sixteen-hours-a-day, one-on-one behavioral therapy. Some children even cured themselves, through tireless, heroic acts of will.

This was the era we lived in for many years after Hannah was diagnosed: the era of the hard-earned autistic miracle. Its culmination, I suppose, would come in the form of an organization, founded in 1995, called DAN!, which stands for “Defeat Autism Now!” The exclamation point, I’ve come to understand, is an essential part of the acronym, for it emphasizes the diehard ethos of the group—emphatic, impatient, and incredibly sure of itself.

Or, anyway, it was sure of itself in 1995. DAN! comprised a registry of doctors who specialized in “alternative” autism treatments that the medical establishment found, and still finds, useless or even dangerous. DAN! doctors were among the most prominent supporters of the medically discredited belief that vaccinations can cause autism. They also advocated the use of megavitamins, along with other dietary supplements and restrictions; hyperbaric oxygen chambers; heavy metal chelation, and a gamut of other biomedical interventions that only once or twice turned deadly. For the most part, these treatments served merely as wastes of time, money, and—that most awful thing—a parent’s desperate, insatiable hope.

Autism was just beginning to seem less rare by then--the early 1990s--and perhaps it actually was. At any rate, autistic children weren't routinely shut away in institutions the way they used to be, so it was more common to know, or at least know of, an autistic kid—to have noticed one at your child's school or in the neighborhood, or to have one somewhere in your extended family, whom you might actually meet now and then at holiday reunions. (As I write this I get a picture of a thousand twinkling Christmas trees being yanked to the floor, all over the world.) The miracle books, as well, and now and then a movie-of-the-week or a PBS documentary, were making the public more “aware” of the syndrome.

In a way we were lucky, having our autistic daughter in 1988, rather than, say twenty years earlier. The fifties and sixties were the era of the “refrigerator mother”—the idea being that children became autistic because their mothers refused to bond with them emotionally. Hardly anyone believes in that theory anymore. No, nowadays—in the 2010s, the time that I'm writing this—we're in a new phase entirely. All you have to do is skim through the list of the 17,798 autism books (as of this writing) on Amazon.com to see that these days it's all about the “spectrum.” Autism, PDD, Rett's Syndrome, Childhood Disintegrative Disorder, Asperger's Syndrome. They're all subcategories of ASD (autistic spectrum disorder), and while they share many of the same symptoms, they may have a hundred disparate causes, and represent a thousand degrees of severity, and should perhaps be treated in four or five dozen different ways. Most of the books on Amazon aren't anecdotal miracle stories anymore, but rather they detail specific, practical, everyday “interventions” that a parent or a teacher might try in order to bring a child a little closer in the direction of typicality. “Cutting-Edge Therapies” begins the title of one book; “1001 Great Ideas” begins another. “Activity Schedules.” “Autism Life Skills.” “A Practical Resource of Play Ideas.”

At the time of Hannah's diagnosis, scientists calculated autism's odds at one in 10,000 children. Nowadays, well, it depends on who's doing the calculating. I've seen figures like “1 in 1000,” but I've also seen “1 in 100.” [From my most recent reading: “1 in 68.”] Any way you look at it, it's an epidemic, they say, even as nobody seems to know its actual scope. The difficulty likely arises from the fact that nowadays doctors are diagnosing not just the clear-cut cases—which, as it turned out, Hannah's was—but also the higher functioning, Asperger's Syndrome types, whose most obvious atypicalities consist of difficulties in social interaction. When Hannah was young,

I'd never heard of Asperger's; it existed, of course, but it wasn't part of the general conversation back then. (It wasn't even an officially accepted diagnosis until 1992.)

In those old days, instead of having Asperger's, people were simply considered "eccentric." These days, it seems we think the other way around. I know that I myself see Asperger's Syndrome everywhere—in Henry sometimes, and all over his side of the family, but on my side too, and in various offbeat friends of ours, and sometimes in myself. I find it comforting, somehow, to think of it as common, to find out you could give it a name if you wanted to, and especially to notice, on the internet and among my friends and acquaintances, how many people with Asperger's are starting to reconcile with and even to take pride in their quirky identities, and how they've begun to find and bond with each other. They've gone much farther than that, in fact: there's a huge and growing movement among "Aspies"—a fabulous nickname if there ever was one—to redefine Asperger's Syndrome, and even autism itself, as a "difference" instead of a "disability," to challenge the commonplace idea that "normal" automatically means "better."

It's a revolutionary notion—and quite likely a great one—and, from my high thin perch on the outside looking in, I afford it much respect. But had it been around in the days when Hannah was first diagnosed, well, I don't know what I could have done with it, day by day, or how it might have changed the ways I thought about, and advocated for, my daughter. Indeed, I fear it might have become just one more thing for my unmoorable heart to try to latch on to, in the same way I tried, vainly, to cling to the word "mild" in Hannah's original diagnosis, or to Dr. Rapin's prediction that Hannah would turn out to be a "chatterbox."

“Remorse is memory awake”

Throughout that first summer, post-diagnosis, we drove to Helena once a week to spend an hour with Theresa, the speech therapist. She worked with Hannah, of course, but just as often she focused on Henry and me, as she tried to train us in the everyday business of developing Hannah’s skills. In her summary report, she wrote:

Information regarding interaction, attention, pragmatics, semantics and play was given to Henry and Nancy. Methods of eliciting words from Hannah were discussed and demonstrated... Other issues as related to autism and language such as discipline and sleeping habits were discussed. Receptive language development, including responses to commands and vocabulary development, was discussed.

And apparently, in her estimation, we did pretty well:

Henry and Nancy exhibited increased awareness of the effects of autism on language and play development. They demonstrated the ability to alter their interactive styles with Hannah and were eager and willing to incorporate suggestions into home activities.

Ah, the official reports. I would collect two big laundry baskets full of them over the next several years—from doctors, speech therapists, teachers, psychologists, social services workers, clinicians, aides. The style of such documents doesn’t vary much. To whatever degree possible their writers try to be precise, scientific, and so objective it’s hard to remember they were ever actually in the room with your child. Only now and then do you get a glint of human warmth. In Theresa’s report, for instance, she sums up Hannah as “a darling three year old girl with childhood autism.” I could have kissed her for adding that simple, unscientific word, “darling.” Dr. G refers to Hannah as “a pleasant child who shows lots of loving affection.” (“Both of her parents seem like excellent observers and historians,” she adds later.) For her part, Dr. Rapin notes that Hannah “presents herself as a chubby, attractive, unstigmatized little girl.” First off, I love that phrase, “presents herself”—as if Hannah strode into Dr. Rapin’s office, shook the doctor’s hand and said, “How do you do? I’m a chubby, attractive, unstigmatized little girl.” I’m further enamored of the words “darling,” “attractive,” “pleasant,” and maybe even “unstigmatized.” (Frankly, even “chubby” sounds delightful, to my yearnful ear.)

I wonder if they're trained to add such words to their otherwise sterile analyses. If so, whoever taught this lesson was incomparably wise, because sometimes those tiny compliments were my life's blood. As I look back over many of them now, my favorite may be one in which Dr. Rapin rather oddly, and, to my mind, endearingly, combined the kindly with the clinical: "Examination shows a lovely little girl whose head circumference is 50.5 cm."

Dr. G arranged for Hannah to undergo a series of clinical diagnostic procedures that summer. Hannah had her first MRI, which showed nothing out of the ordinary. She was tested for Fragile X Syndrome, which she didn't have. Her hearing was evaluated—I wish I could remember exactly how they managed that—and determined to be normal. She had several blood and urine tests whose detailed results lie in front of me as I write this, each report ending with the phrase, "No diagnostic findings."

The reports and tests ended up in a heap that soon became a mountain of information (and misinformation—although to this day I'm not entirely sure which is which). I bought or was given a plethora of books, either clinical or practical or anecdotal. Every institute or school or support group I called or wrote to, sent me their standard stack of pamphlets and brochures. As well, I compiled mounds of monthly newsletters put out by the organizations I'd joined: the Autism Society of America, the Autism Research Institute, PLUK (Parents, Let's Unite for Kids), the Indiana Resource Center for Autism, MAAP (More Able Autistic People).

Henry's father, Irwin, began to send me every New York Times and Wall Street Journal article he could find on the topic of autism or learning disabilities in general. "Doctors Report Breakthrough in Treating Autism," reads the headline of the one before me now. (It deals with a study in which the drug naltrexone, used more commonly in the treatment of heroin addicts, seemed helpful in alleviating hyperactivity in autistic children.) Meanwhile, my mother sent me first-person miracle stories from *Reader's Digest*, *Redbook*, *Woman's Day*. "Can Autism Be Cured?" is the title of the *Woman's Day* article, which can be summarized by its blurb: "From birth this zombie like girl seemed hopelessly unreachable. Then a simple two-week treatment turned her into a normal young woman."

I used to make lists of the various treatments and therapies I read about, so that during our visits to Dr. G, I could ask her about them. Dimethylglycine, fenfluramine, periactin, cloripramine, Ritalin, Zoloft, Prozac, Vitamin B6, Tegretol, clonidine, Dilantin, naltrexone, Risperdal, Luvox, Clonazepam, folic acid, ginkgo biloba, secretin, gluten-free diets, epsom salt baths, Auditory Integration Therapy, Music Therapy, Holding Therapy, Play Therapy, Sensory Integration Therapy, Dolphin Therapy. Dr. G listened to my questions patiently, and with an air of utter unsurprisability. I swear, among my list of alternative therapies I could have listed “Brain Transplant” or “Bathing in the Blood of Virgins,” and she’d have kept nodding that dispassionate, owlish nod of hers—after which she would dismiss each item on my list, one by one. “That study’s never been replicated.” “That treatment is supported by anecdotal evidence alone.”

Still, over the next several years we tried many of these alternative therapies, and more. In most cases there was no reason not to, after all, if you could afford the price of their implementation (\$35 for a month’s worth of megavitamins was doable; \$2200 for a five-day program at Island Dolphin Care in Key Largo, Florida, was not), if you were careful to monitor the side effects of the drugs, and if you tried your hardest to perform the therapies correctly.

But the thing is, I made so many mistakes along the way. I didn’t keep close enough track of what we had and hadn’t tried already. I didn’t always comply with the diligence some of the therapies required. I gave in to Hannah at times when I was supposed to hold firm. It turned out that while I could always be counted on in sudden emergencies—quick to put out the wastebasket fire, to swerve around the deer in the road, to catch the wine glass before it hit the floor—I was a clumsy, erratic wreck in the face of the ongoing, ever-changing crisis my life was becoming, day by day by day. And I could never tell whether *that*—my lack of discipline and consistency--was the main reason I could never discern any actual, sustained results from anything I tried. I still don’t know this, in fact, and it’s the question that’s continued to haunt me, even as, in the years that followed, so very many of those treatments and therapies have been, to one degree or another, debunked.

It’s haunted me pervasively, and for so long, in fact, that there were several points during the years since Hannah’s death when I might have ended this book right there, on that word:

“haunted.” For such a long time, you see, it was as far as I could go. My feelings about Hannah’s life and death were so clouded and shivery, my mind so disturbed by the ghosts of all the things I might have done differently: all the paths—from well-lit six-lane highways, to jungle trails so densely overgrown you’d need a machete to get through—all the paths not followed to the end.

“Hope is a subtle glutton”

Diary entry, August 18, 1991:

And we’re thinking of having another child. Does that seem crazy? I don’t know. I’m 32. I feel like life’s passing fast. I feel like I ought to get on with it. But I’m scared of taking the focus off Hannah, and scared it’ll be somehow like giving up on her. Still, maybe it’ll actually help her—some people say that. You can find an expert who’ll tell you anything, and you don’t have to look that hard either.

I spend a lot of time on the phone, trying to amass information. I read a lot of books. All the theories are contradicted by other theories. Meanwhile, all the theorists seem so utterly sure of themselves. They’re like competing theologians. Is this the way it is with all diseases and therapies? Is there a church of chemotherapy, a church of radiation, another church where all you drink is wheatgrass tea?

Wouldn’t it be something if Hannah did “grow out” of this, the way some people seem to think she will? I’m not beyond that, not beyond thinking that crazy hopeful way. But I push it back. If I give in to it and it doesn’t pan out, it’ll kill me.

Henry and I went to a counselor—I’ll call him Bob—to try to get a handle on our grief. We saw him maybe six times, all told, but there was something not quite right about our therapy from the start. As I wrote to a friend at the time:

We’re going to therapy. But the therapist—we’re concluding after having spent \$480—isn’t so great. Henry doesn’t like him, and I like him well enough but don’t trust him. He often seems to be making things up as he goes along, and meanwhile pretending he’s smarter than he is, that he has some mysterious master plan that we’re best off not knowing. Plus he wears weird flowered pants.

Bob seemed ill at ease with us, and I began to get the feeling that he was intimidated by Henry, who was, after all, a college professor with a Ph.D. It was the sort of thing we’d run into—and still do—once in a while in Butte. Henry has a lingering New York accent that seems to discomfit some Butte people; for one thing, they tend somehow to mistake it for a British accent (thus automatically superior to their own), and it doesn’t help that Henry is the sort of person who, without thinking about it, uses words like “heretofore” and “notwithstanding” in everyday

sentences. I myself, on the other hand, have spent my whole life cultivating the common touch. I grew up in an anti-intellectual family (a sort of microcosm of Butte, I suppose), and as a result I've learned to tone myself down, to drop my "g"s and avoid polysyllables—to become, in my everyday interactions, the most non-threatening person on the face of the earth.

The moment we were able to put together what the problem was with our therapy happened during a session in which, as we once more recited our lamentations, Bob said, "I understand why you're disappointed. You're such smart, educated people, and now you're afraid that your child may not go to Harvard."

Harvard? We were nonplussed. Who on earth did this man think we were? No, we were not worried that our child wouldn't go to Harvard. We were worried that she'd never be able to say her own name, much less speak in sentences, make a friend, live on her own, have any semblance of a normal life. Harvard. When we could speak, we murmured politely that no, actually, that wasn't our primary concern, and we put an end to our sessions. A year or two later, we read in the paper that Bob had been arrested for health insurance fraud, and had had his counseling license taken away, all of which was neither here nor there, of course, but we took some vague satisfaction in it anyway.

“I can’t tell you, but you feel it”

Letter to a friend, August 21, 1991:

For nearly three months now, this keyboard has been moldering, and today I just couldn’t stand that anymore, so here I am, back at it, if only for a brief letter to you. I’ve been itching to return to writing fiction—I’ve got the first draft of a short story ready for revision, and lots of ideas for it (or so it seems to me, in the abstract), and then I have this partially thought-through novel to get started on. But I’ve got this list of chores too—stuff to do with insurance claims, Hannah’s pre-school arrangements, letters, phone calls. (Even as I wrote that line, I realized I had to call the pre-school, so I did that, and now it’s fifteen minutes later.) Hannah’s at daycare four hours a day these days, and at the start of the four hours I always stand here sort of stunned and blank, and I waste a good five or ten minutes just figuring out what to do first.

Last night she slept through, for the first time in a week. I’d thought we were through with sleeplessness, but since the New York trip she’s been moody, off-kilter. It was a rough transition for all of us, really. We’ve spent the last couple of weeks feeling depressed, I think, because our time in New York was so soothing, so full, and there were all these good people there who loved and took care of us. And now we’re back to nothing and nowhere again.

Hannah, like Henry and me, misses her grandparents—which is a very good sign for her, really, but of course it feels sad too. Henry’s parents were wonderful to her. They’d shove us out the door—it was almost like the old days, all that time to explore the city, go to movies, see friends, have dinner in weird restaurants—and then they’d guide Hannah toward her own adventures. Playgrounds, swing sets, car rides, frolics in the wading pool—the Gonshaks know how to show a kid a good time.

And after a couple of days of looking suspicious, Hannah embraced the whole thing. She loved exploring the old house—lots of stairs to climb and doors to slam—and pretty soon she loved her grandparents too, I think. (Whenever Henry’s father sat in a chair, she’d go over and sit directly on his feet—a very high honor for him, needless to say.) Now over and over she’ll ask for their picture to be brought down from its shelf, and she’ll say

“Rama” (a sort of collective noun for the pair of them) again and again, and she’ll kiss the picture if you ask her to. It’s all very poignant—do you know I think I even saw Henry’s father crying, on the afternoon we left them? Sometimes I’ve been thinking that a really good vacation is worse than a rotten one, especially when there’s so much time before another one’s due.

Now here it is, a week before school starts, and summer—and with it the languor, the leisurely pace that only people like us who’ve never had normal 12-month jobs could take so easily for granted—will be over. And then Henry will be tense again (make that “tenser”), and I’ll be nervous, as I am already, about sending Hannah into the wholly new world of this pre-school, and worried that she’ll have trouble adjusting, and that they won’t do right by her there. The doctors have all told me to stay involved, to work with the teachers to make sure they know what Hannah needs, and I’m afraid I won’t do that—that I’ll be too timid, too under-informed, or (worst of all) too lazy to monitor everything. I keep running up against the same fear: all this responsibility—Hannah’s education, Hannah’s life—on my head. How I long for an expert, someone I can trust implicitly, who knows the right course, and who cares enough and has the time to follow it through. If I were rich I’d hire somebody. Hell, I’d set up my own institute just for Hannah. But I don’t know that that would ease the worry. The scary thing about this—one of the scary things—is knowing that there are no experts. Everybody, even the people making two hundred dollars per office visit, is just shooting in the dark, and your own shaky aim is as good as anybody’s and probably better than most.

The other thing I long for—one of the other things—is that Hannah will take charge of herself, fundamentally, the way other kids seem to. Sometimes I see it—that inner drive I once assumed all kids had, the thing inside that makes them want to learn and grow. Sometimes I think that’s the only thing Hannah lacks, and the only thing that’ll save her. The reason she’s not more involved with the world, I think, is that the world doesn’t interest her. She’s not fascinated by it the way she is with whatever wonderful, all-consuming thing is going on in her head. Sometimes I watch her while trying to imagine what it is that entrances her so. Something she hears, maybe—the rush of her own blood through her body, the high drone of her nervous system at work. And I try to get inside

with her, to know life the way she does. Often, even when I'm not trying, I find myself staring off, unfocused, unthinking, and I can feel in myself how soothing it is, like meditating, or like being drugged. I think of Hannah, locked in that, and I can imagine, I think, how difficult it would be to respond to the outer world from so deep, deep down. I can imagine not feeling the need to respond, not seeing the point.

Then sometimes I see that she's not so buried as that. Last evening—it was one of those hundreds of times during the day when I'm too exhausted to think about “working” with her anymore, and all I want to do is fold in on myself, and I'm sitting on the exercise bike, either riding it or else just perching there, out of reach, because I know that if I sat down on the couch she'd rush over, wanting to nurse. Hannah stood looking at one of her books, turning the pages and saying all the right words for each picture, “This baby's sleepy,” or “sitting,” or “crying, boo-hoo-hoo.” She labelled even the pictures I didn't know she knew, I didn't think we'd been over them enough: crawling, biting, eating lunch. Throughout the day there are dozens of moments like that, at least among those that I notice, where Hannah's there, where she picks up fast on what I've been teaching her, or where she's learned something I wasn't even trying to teach her. And, I think, without those moments, without something miraculous happening every single day, I wouldn't know how to survive this. (Yet there are people who have to, somehow, and do—I've read their stories in books, I've talked to a few of them on the phone... Or maybe it's just that they've trained their eyes to notice even all those tinier miracles that the rest of us tend to miss?)

Hannah and I were playing with her doll—teaching her to pretend, that's one of my jobs. She herself loves to “go whee”—be lifted in the air and spun around. So in my dollyvoice I said, “More whee, please,” the way Hannah says it to us, and I lifted her doll in the air. It was a whim, and I wasn't expecting much. Hannah generally loses interest in pretending after only a few seconds—but she took to it right off, she thought it was the funniest joke, and she wanted to do it herself. “More whee,” I'd say, and then she'd lift her dolly up in the air. And since then we've gone on in this direction, and now when I have the dolly say, “Little something, please,” which is Hannah's (constant) request for

nursing, she'll hold the doll to my breast, and occasionally even to her own, and she finds the whole thing pretty hilarious.

All day long, I go up and down. Mostly it depends on how much sleep I've gotten—the last nights have been rough that way. I'm trying to live a life somehow, trying to take care of myself, take time off, get exercise. Sometimes I'm all right, and sometimes I'm nearly as aggrieved as I was at the beginning of all this. (How long ago that seems now—May 20.) I rely on time to take care of me—it's a blind faith, and sometimes it's all I have. I figure if I just let this thing happen to me, and give myself time, someday I'll feel—what?—normal, maybe, whole, better. I don't know. People get over worse things—they haven't much choice. I read in the paper—you don't have to look hard, but I'd scour the news if I had to because for some reason I need to read these things—about awful tragedies. Accidents mostly—car wrecks, plane crashes, farmers who get caught in threshing machines, hikers who get mauled by bears. The sort of public catastrophes that reflect only a little bit of what's really happening out there. It's increasingly amazing to me that, tragedy being so ubiquitous, it's so very rarely talked about—but I guess I've pontificated on that subject to you before.

“Where every bird is bold to go”

September came, and I brought Hannah to the special education pre-school that would become, as it turned out, her second home for the next three years. There I met with the teacher, Sandi Morris, a pretty, middle-aged woman with the delightful ability to remain serene and even perky in the midst of pure chaos—a class of ten or twelve young children with a variety of disabilities, and each of them needing some very particular thing from her at every moment of every day. A few of the students were physically as well as mentally disabled—confined either to wheelchairs or to crawling across the floor. Others were, to varying degrees, simply “slow learners.” Hannah was the only autistic child in the class, and—to my disappointment—one of the very few autistic children Sandi had ever worked with. But she was eager, you could tell from the start—eager to learn new tactics, assuming anyone knew any—and she had good instincts about children in general. She and Hannah liked each other right away, and Hannah was happy to be in the classroom, with all its various and colorful distractions.

Sandi’s husband, Tom Morris, happened to be one of the school district’s speech therapists, and he also spent a lot of time with Hannah. He too was enthusiastic by nature, and he and Sandi shared a sort of twinkly good humor, which, I’ve since come to think, was the most essential quality for a teacher or aide to have when dealing with Hannah. Together, Sandi and Tom put me at ease, at least a little. They were “two of the most caring, well-intentioned, kind people I’ve ever known,” I wrote in my diary only a few months after meeting them, and they made me begin to think that staying in Butte might not be such a horrible fate after all. True, they lacked expertise in autism—the whole school district lacked that—but they were willing to work hard, to read up, to learn, and to collaborate with me in whatever big or little ideas I might bring them.

Still, Hannah’s first couple of months in Sandi’s class were hard on everybody, because Hannah was simply incapable of (or perhaps just not interested in) following directions, or even sitting still for any length of time. The rest of the kids might be gathered on the floor for a story or lesson, or sitting at long tables with crayons or other craft projects in front of them. Hannah could be convinced to sit among them, but in a matter of seconds she’d be up again, wandering the classroom, pulling tubs of blocks or beads from their low shelves, or making a mad, brave dash for the corner where the afternoon snacks were stored. And if, indeed, she would sit down

for a minute or two, she would jabber distractingly, or face the wrong way, or chew on crayons, or rub play-doh into the floor mats.

Though Sandi and her classroom aide did the best they could, they had too many other responsibilities to attend to Hannah every minute. For a month or two we were stymied. Finally, sometime around the time of Hannah's first official school evaluation, in November of 1991, I got an idea from a book I was reading: that Hannah should have her own personal aide to keep her on track during the day. In the book this person was called a "shadow," someone who would follow Hannah everywhere, steer her in the right directions, keep her from eating the crayons, etc. Sandi and Tom agreed that providing a one-on-one provider for Hannah was a fine idea, and now the only problem we faced was in finding the funding to hire one.

We made an appointment with Mr. C, the director of the district's special ed division, and, as we'd been warned ahead of time by the books I was reading, and from Tom and Sandi themselves, we braced ourselves for an uphill fight. So many parents, in both the handbooks and the miracle books I was reading, had actually had to sue their school districts for the extra help their children needed, and we were afraid we might need to go that far too, which was something we both dreaded, and even feared we lacked the stamina to endure. Still, we knew at least the gist of our rights: according to federal law, every child is entitled to the education that's best for her, regardless of cost.

Our visit with Mr. C got off to a rocky start. Though he'd never met Hannah, he agreed that a shadow would probably be good for her. But then he shrugged and added, "I'm afraid the funding simply isn't there." He went on to suggest that we might want to ask for money from, say, our health insurance company, or a charity group, or perhaps some mysteriously beneficent source at Montana Tech.

I remember Mr. C as a smug little man with a bad comb-over. (I also remember him leaning back in his chair with his feet up on his desk, and his arms raised and clasped behind his head, but I don't suppose I'm right about that.) For a moment we were taken aback by his shrugging, complacent demurrals, and I remember thinking that this might be one of those times when Henry's "British" accent and hyper-articulateness might serve us well. Yet my forlorn husband

could only sit there mute, seemingly shrunken, ready to acquiesce. So I found myself doing the talking.

“The thing is, though,” I said, or words to the effect, “it’s the district’s responsibility to provide Hannah with whatever she needs to get a good education. As it is, we’re settling—she really needs much more intensive speech and behavioral therapy, and greater expertise, than you’re providing right now. We can bring you letters from experts detailing her various needs. We can bring in lawyers too—isn’t that usually the next step in these cases?”

What happened then—after just that little soft-spoken paragraph—served ever after as a lesson for me. Mr. C, who had seemed so authoritative, so stuck to his guns, sitting there behind his big black desk and smoking a fat cigar (but of course I must be making that up about the cigar), quite suddenly, simply folded. Apparently, though I never even fleetingly thought of myself as one of those tigress mothers from the miracle books, I could, when called upon, sound a tiny bit like one, and occasionally that was all it took. We got the shadow.

First we had to put it in Hannah’s IEP—her Individualized Education Program—which is the binding document, the blueprint for a disabled child’s everyday education. Over the next several years the IEP would become just another of our child-rearing rituals: we would all gather—parents, teachers, psychologists, therapists, social workers, occasionally the school principal and/or special ed director—at least twice each year to develop this program, which covered everything from the frequency of her speech therapy sessions, to her personal-hygiene routines, to our request for bus transportation.

The resulting document was usually thick and detailed. Through the course of our discussions, we all would camouflage our general cluelessness by declaring that Hannah should fulfill six or seven “goals” for the upcoming school term. She would, for instance, “improve [her] functional communication skills.” Underneath this general heading, we’d list nine or ten particular “short term objectives.” These would include such precise, measurable goals as “Increase Hannah’s ability to point to 1 to 4 body parts consistently” or “Hannah will respond with ‘Yes’ or ‘No’ to a simple request.”

From 1992 onward, the goal listed first on Hannah’s IEP was always, “Hannah will have a fulltime monitor to assist her in the classroom and throughout her school day.”

Sad to say, but I don't remember Hannah's first few shadows very well, over the course of her three years of pre-school. They were women, I'm sure of that much, and they were nice, and it's eminently possible that they were named Linda, Mandi, and Suzanne, and that each one lasted about a year. They had no particular training, but their roles were simple and clear—they followed Hannah everywhere and assisted her with classroom jobs as well as lunchroom and bathroom activities. Beyond changing a diaper now and then—it would be eight more years before Hannah was toilet-trained—nothing overtly courageous was required of them. At this point, Hannah's shadows needed, merely, to be paragons of patience, compassion, and energy. It would be at least another couple of years before we'd need to add, to this list of job requirements, the word "heroism."

“I measure every grief I meet”

During one of our early visits, Dr. G asked me about Hannah’s “behavioral problems,” and seemed startled when I replied that she didn’t have any. No tantrums? she asked. Not really, I answered. Hannah was frustrated when she didn’t get her way sometimes, but she bounced back quickly. Her only real problem, which I was so used to by now that I’d pretty much forgotten to be bothered by it, was that she seldom slept through the night.

Dr. G suggested a more or less “natural” treatment: three-milligram melatonin pills to help with Hannah’s sleep. As I recall, they may have worked a little bit. Or maybe—caught in the hope-heavy self-delusion that traps every parent sometimes, leads us blithely along a path toward devastation—I just really really wanted to *believe* they did. At any rate, it would take a few more years, by which time Hannah was taking 150 milligrams of Trazodone every night, that she finally, or at least more often than not, slept through from bedtime to dawn.

These early days also marked the beginning of our lifelong relationship with Family Outreach, a social services agency funded by the state to work with disabled children throughout Butte-Silver Bow County. Hannah’s personal case-worker was named Carolyn—a petite, friendly woman with a voice so sweet and trembly, so sing-song—she reminded me of Glinda the good witch—that it came to serve for me as a cautionary tale of what can happen when you spend your whole career working with children. Carolyn would come by once a week for an hour or so. She spent part of her time playing with Hannah, pulling out toy after toy from the big tupperware container she hauled with her in her car. She and her toys would fascinate Hannah for an entire half-hour at a time, at least during the first months of our weekly sessions. Then, after each playtime, Carolyn would sit down with me, and we’d talk casually about whatever had happened since she’d last met with us.

Carolyn videotaped Hannah a few times over the next few months. That is, I held the camera while the two of them pawed through the tupperware treasure chest in hope of finding some toy that might hold Hannah’s attention for more than a few seconds. These taping sessions were just “for the record,” I guess, since, so far as I know, no one so much as glanced at them later, much less compared them to previous videos, or tried to discern Hannah’s strengths or interests or progress from the stories they told. Nobody but me, anyway, and two decades would pass before

even I studied them closely, lapsing into a state of nostalgic wonder at how smart and, ah, how bright and happy Hannah had been at the age of three and four. I still find it breathtaking—and even more, I feel an urgent, crazy upsurge of *hope* (of all things)—as, for instance, I watch my darling girl insert every yellow shape into its matching hole on the shape-sorter ball. She needs only ten or twelve seconds to complete this task. Even more fascinating is the fact that she barely glances down at the ball as she inserts the shapes—she seems to know by touch alone which piece goes where.

In the videos you can see the beginnings of Hannah’s lifelong obsession with Play-Doh and other malleables—Koosh balls, bean bags, dolls with bendable arms and legs. She loved all things squishy, pliable, breakable—loved them with the same trance-like obsessiveness she showed in her love of music. (Which reminds me that nearly every one of the videos of Carolyn and Hannah, and so many others I took of Hannah alone over the next several years, has an endless, accidental soundtrack: Raffi or Sesame Street or else those trippy, so-bad-they’re-great “KidSongs” and “Wee Sing” videos that Henry’s father liked to send us.) Her fascination with tactility led to years of unlikely Christmas presents. Bendy straws, fuzzy pipe cleaners, paperclips, scotch tape, shower-curtain rings, velcro strips, bubble wrap, squeaky rubber chew toys from the pet department.

At one point during those early post-diagnosis months, Carolyn put together a local support group for parents of disabled children. Apparently unembarrassed by my decrepit little house with its mustard-colored walls, I hosted the first meeting myself, on a chilly evening in the spring of 1992. Our group consisted of five or six mothers (no fathers besides Henry—perhaps they were all back home, babysitting), and I remember it as something of a bust, dominated as it was by the non-stop complaints of one particular mother, whose son had Attention Deficit Disorder—a diagnosis that’s very common these days but was rarely recognized twenty years ago. Thus, among the bigger obstacles she faced was in getting the school district to acknowledge the boy’s disability in the first place. They insisted on treating him as “normal,” so he wasn’t getting the extra help he needed.

And surely it should shame me to say this—because I know, I really do know, that ADD can be a serious and maddening disorder—but all I could think as this mother went on and on about the district’s insensitivity to her child’s needs was, “Well, wouldn’t that be nice, for your child to

seem so normal that your biggest problem is getting the school to believe in his disability.”

Though of course I didn’t show it, this woman’s grievances angered and frustrated me, and I was actually glad for the occasions when three-year-old Hannah would sweep into the room, whoop like a hyena, and leap into a balanced pose on the backrest of the couch, where with one hand grasping the orange drapes she would jump up and down, causing every mother’s tea to quiver in its cup. You call your kid disabled? I thought, perversely proud. Ha! *This* is what disabled looks like!

There was another mother at the meeting, a very young, dark-haired woman, who told her story briefly and didn’t say much thereafter. Her son had a degenerative brain disorder. At birth he’d seemed normal, but by now, at the age of three, he’d lost all the skills he’d been able to gather, and now he lay flat in his crib all day, moving only spasmodically. Nowadays her son had to be fed intravenously, since he’d lost the ability to swallow food. Nonetheless, his eyes remained clear and lively, his mother told us, and she was sure he still knew who she was by the way they’d brighten as she cooed to him. It wouldn’t be much longer—a few months at most, the doctors predicted—before the little boy’s organs would begin to shut down, and he would die.

All through the rest of the meeting, as the others told bits of their stories, I watched this quiet woman, who seemed too young to have a child, much less to be enduring such pain. I kept hoping she’d talk again, and I wondered what she must be thinking and feeling. Her demeanor was calm, patient, inscrutable. Was she wise? I thought. Had she come to terms, somehow? What did life look like to her? What was it like to know what the future held? What was it like not to have *hope* to cling to, or to contend with, anymore?

Our little support group may have had a couple more meetings, I’m not sure, but it fizzled out pretty quickly after that, and, unless somewhere along the line I’ve passed them, unwittingly, in a grocery store aisle, I don’t think I’ve ever seen any of those women again. Maybe we just weren’t ready for each other’s pain. Maybe we were so caught in the “everything’s fine” dissemblance our daily lives required that we no longer knew how to bear authentic witness to each other. Or maybe we were just worn out.

“I breathed enough to learn the trick”

From a letter, early 1992:

In the midst of such turmoil [a fight with Henry], I may be forgetting one good thing that seems to be happening more and more, and that's that the Hannah grief is getting easier. She's doing so well these days. Talking more and more. Suddenly she's incredibly affectionate, all over me lately, as if I'm just the most delightful thing and she's only just noticed it in the past few weeks. All over the dog too, who's not nearly so thrilled about it, but of course he doesn't understand what a good sign it is. (Or maybe he does understand, but simply doesn't care—I wouldn't put it past him.) We've still got a long way to travel, but I'm full of hope these days.

It's amazing how you can get used to things. My mother flew up from Colorado to visit us in the summer of 1992, and as my daughter climbed the drapes (or something), I was casually telling Mom that taking care of Hannah wasn't really all that hard. “Oh, Nancy!” my mother exclaimed, in one fast reflexive breath. She said nothing more, but merely sat there on the play-doh-crusted couch, shaking her head. She, my mother. She, who had pretty much singlehandedly raised nine kids on her own, my father's work (train engineer, union rep) taking him away from home for days or weeks at a time. (To be sure, Dad's absences were generally considered by all ten of us to be more helpful than his occasional, volatile presences, but that's neither here nor there.) My mother, who had always, perhaps not purposely, encouraged her children to feel as if—one by one, or all at once—we'd forever been the heavy cross she'd had to haul uphill, alone.

It was, I think, the best compliment she ever gave me—that seemingly involuntary gasp of “Oh, Nancy!” It astounded me: the very idea that Addie Coughlin, my mother, should find my life with Hannah difficult. The fact that I remained so generally cheerful every day must mean she thought I was managing it pretty well, I decided. And if my mother, of all people, should think this way, then perhaps my life *was* hard, and perhaps I *was* managing it well. Neither idea had occurred to me for even a moment in those days, after the grief of the diagnosis had lessened, but before the hardest times began.

That same summer, in the course of which Hannah would turn four years old, we made our annual New York visit. One day in my in-laws' kitchen, I was having breakfast when I heard Henry's mother, Avis, let out a cry from the TV room. I found Hannah sitting there, blissed out,

in a rocking chair, covered from head to toe in baby powder. Somewhere in the house, she'd found a full container, and had taken delightful advantage. Avis stood there, barely able to contain her fury—my parents-in-law ran the most fastidious household in Queens—but you must believe me when I tell you that the scene was, maybe even *objectively*, just plain funny. This little albino version of Hannah, hooting and rocking within her talcum utopia, dark eyes gleaming from a ghost-white face... Maybe you had to be there. At the very least you had to be casual. For just those few seconds that passed before I could help myself, I laughed along with my crazy daughter. I took delight in her delight, all the while knowing we were only making Avis madder.

It was simply the way of things: broken lampshades, stained carpets, curtains half torn from their rods. We had to hide the TV remote so she wouldn't pull the buttons out. We put a lock on the cabinet where we stored the CDs. We couldn't have plants anymore, much less vases, knickknacks, anything easily broken. I kept a keen eye on the canned goods: Hannah liked to peel off their labels, so that we often had to guess at their contents. (Come to think of it, there's still an unlabeled can in the back of my cupboard that I have neither the heart to throw out nor the nerve to open.) Later on we had to lock them up too, when, around the age of seven, she taught herself to use the electric can opener. Eventually we had to lock away just about every destructible thing, with ever more sophisticated locks as Hannah grew more and more clever. Locks on cupboards, refrigerator, freezer. Locks on every gate, door, and window. Happily, we used the simplest, 0-0-0 combination for each one, or we'd all have met a silly, grisly end: trapped inside our house, and starving.

Still, no matter how vigilant we were, things got spilled (dog food, crackers, parmesan cheese) or destroyed (books, eyeglasses, CDs, couch) all the time. And somewhere amid the pattern of such everyday losses, I learned the most basic of all the lessons Hannah taught me in her lifetime: the trick is not minding.

By this time we'd bought and moved into a new house—a nice one this time (and not just by my ever-lowering standards), with two floors, four bedrooms, and a fenced back yard for Hannah and the dog. It was harder to keep track of Hannah in this larger space, for though she usually stayed near me, occasionally she'd wander from room to room or even outside. One day I entered the living room to find her sitting in the cold fireplace, covered in soot, singing her usual

jibber-jabber song, and this time the scene struck me as so funny—and such a portrait of contentment—that I had to take a picture before hauling her upstairs to the bathtub.

Another day I let her play in the back-yard sprinkler, got distracted for a minute, and looked out again to find her gone. She hadn't gotten out the padlocked gate, nor was she inside the house. It took a few minutes, but then a glance through the living room window showed Hannah in full frolic in the *front* yard now, and upon investigation I noticed for the first time that there's a two-foot-wide gap between our house and the house next door (in the old days, Butte houses were built very close together), and that Hannah had sidled through it to escape. I examined the space more closely, and saw that for some reason—likely because our next-door neighbors were hooligans—the entire pathway was littered with broken beer bottles. Yet Hannah's bare feet were free of cuts.

And it was this sort of thing that made me start to see my daughter as invincible. In later years, whenever she balanced, naked, on top of her redwood swing set, or leapt, fully clothed, into the deep end of a swimming pool, I found myself remaining calm even as other people in the vicinity gasped and gulped. Deep down, beyond the reach of logic, I seemed to feel that Hannah maintained an immunity to everyday hazards—that fate had done its worst when it made her autistic, and now there was little further harm it could do.

“It’s such a little thing to weep”

From my diary, late 1991:

The grief over Hannah has taught me one thing—that you don’t die. You want to but you don’t. You keep on. Gradually you feel better. Not that that’s ever settled and over with, that grief. It comes back, it’s here right now... But it’s not like it was, those first nights, weeks, months. Time heals you, sort of. You live. I’m far from being consoled by that now. It’s just a fact I know about: for better or worse, nothing kills you.

By the start of 1992, we’d begun work, employing our usual precise scientific methods, on conceiving another child. In March I got pregnant but had a miscarriage three weeks later, so surely grieved less than I would have, had it happened later. Instead, I felt confused, ambivalent.

I remembered that in the third month of my pregnancy with Hannah, back in 1987, I’d also found myself bleeding, off and on, for the course of a day or two. We were visiting New York at the time, and I remember not only my own alarm upon seeing the first spots of blood, but also Irwin’s (Henry’s father’s) panic, tautly contained, as he telephoned the family doctor to ask what I should do. Bed rest, the doctor said. So for the remainder of the trip I lay upstairs, while Avis and Irwin brought me soup and magazines.

I was so afraid of losing Hannah then. Only many years later did I risk inspecting a fact I already knew: that early miscarriages are often the body’s response to fetal “abnormalities.” That door opens onto a path that, like so many others I’ve traveled, leads nowhere fast. Should I have surrendered, in 1987, to that blood and cramping? Should I have let our bodies—Hannah’s, mine—decide for themselves our lives’ best course? (Answer: I *couldn’t* have surrendered, not for all the world. Maybe Hannah couldn’t have, either. And what difference our mutual stubbornness made, I still don’t know. I have a curious sense it made no difference at all.)

Moreover, should I be—was I?—glad for this miscarriage now, in 1992? There’s something a bit sad about fearing your own womb. Feeling helpless in the face of the embryo’s stormy internship there—all that must go right, all that can go wrong. Throughout my first pregnancy, except for the early blood-scare, I’d felt foolishly complacent. Not so much so, next time.

Meanwhile, Henry and I were as tense around each other as always—it seemed our default relationship. Sometimes it was manageable:

We work through it time after time [I say in the diary]. We talk in terms of “starting a positive cycle.” We talk and talk. And it partly works. Really, I’m not saying there’s anything dramatically wrong with this marriage. But there’s this nagging habit of suspicion, resentment, that we carry around all the time.

And sometimes it would simply explode:

Henry and I have just had a terrible fight [I write to a friend in June of 1992], a continuation of the fight last night, and maybe at some point I’ll put it all in perspective. But right now I don’t know how I can keep living this way, while at the same time I don’t know how I can leave...Right now it seems to me that Henry is so deeply flawed, so selfish and paranoid and so very angry all the time—I don’t know, I can’t see that he’s redeemable... He feels attacked so he goes on the attack...Over and over I’ve said, “I’m not angry with you, I wasn’t judging you, I was disappointed with this or that, but...it wasn’t a moral issue, it was only a small mistake, and you’re not a bad person...” It’s become a litany by now, and he’s stopped hearing the words and just hears the drone, and it makes him angrier... Right now I feel hopeless, I think that I can’t and shouldn’t keep living with a man I trust so little to remain sane and loving, a man I spend so much time tiptoeing around, a man I fear so deeply... But how long can I think that way? Because leaving feels so impossible—Hannah set up in a good school, me with no money and no job, all that upheaval.

Henry felt stuck in his life—stuck in his job at a college that he thought of as podunk and that allowed him little time to do the sorts of research and writing that would make him a good candidate for some more prestigious haven. He felt stuck in Butte, for even though we were finding a group of natives and “expatriates” (as I thought of us) to become friends with, the place had little to offer in the way of culture—not even an indie movie theater or a well-stocked bookstore (two things that were—or anyway, seemed— much more important in the dark, pre-internet, early 90s), and only one good restaurant in the whole town. And though he didn’t say so, Henry felt stuck with me and Hannah, one of us not pretty enough, not sexy or dynamic or tolerant or whatever it was that I, like a chameleon in reverse, lacked in every context I found myself in; and the other one—well—unknowable, and a constant source of stress and worry.

Meanwhile, Hannah remained the center of my life—which was certainly another problem Henry had with me, and perhaps rightly so, even as he admired and felt relieved by my devotion to her, my seemingly endless patience. She and I still spent hours a day just rolling around the family bed, nursing less and less these days until eventually that petered out completely, but playing peek-a-boo and itsy-bitsy-spider, burying each other under the blankets, or just staring and grinning into each other's wide-open faces.

But the first signs of trouble, the first cracks in my maternal façade, began around that time too.

Diary entry, June 19, 1992:

Hannah woke up at 3:45 this morning and spent the next couple of hours whining, crying, pinching, trying to get up. At 5:30 I finally let her. What a nightmare those times are. I'd been up late in the first place—the omnipresent insomnia. I'm going on no sleep all the time. Then I worry that that's why I'm not pregnant... Hannah's more affectionate with me these days, but also more needy. I get the full force of both her love and her frustration. Sometimes she seems to be giving me both at once. So little progress. I thought she'd be talking more by now. She makes requests—juice, cheerios, lollipops... More water, open door, take off shoes, change diaper. And that's about it. She used to do animal sounds, she used to label things for you—not much of that anymore. Why? She learns a skill, uses it a while, then drops it from the repertoire. And what should I be doing? Should I push more? Should I prevent her from reverting, somehow? No more music so she can't just sit there rocking? The thing is, even apart from what's best, I'm just too tired to do much more than I'm doing now. Every day I begin with a dozen good intentions, and every day I get so little accomplished.

That summer I attended an autism conference in Billings, some three hours from Butte.

Afterwards, the speaker I remembered most was a man named Thomas Powell, who was dean of the education college at the university there, and who had an autistic son of his own:

It was a stirring talk [I write in the diary]. He said that having a child with autism doesn't have to be the center of a family's life. And he said it doesn't have to be a negative experience. He illustrated those ideas, gave examples, told stories. And now, weeks later,

I can still hear those things, and I want so much to believe they're true. Sometimes I do believe them, on days when Hannah's doing well, when she's loving and content, and maybe making some progress. But other days, these days, I lose all perspective, and all hope, because she's moody and difficult and demanding, and she seems to be going nowhere at all.

“I many times thought peace had come”

The following is something I wrote years after the fact, when Hannah was in her teens—a fragmented piece, apropos of nothing, written just so I’d continue to remember the moment, and have some record of the memory:

This happened on what, by our standards, was an ordinary night. It was maybe a year after the diagnosis; Hannah was four years old. We were in the living room, and I was holding her, rocking her, in the La-Z-Boy. In those days she still liked being held, at least by me—I’d kept her used to it, I guess, by all the nursing, which was something she still loved so much that I’d given up the habit of bathing very often, because I knew how much she enjoyed breathing in my sour, mammalian smell. But right now I wasn’t nursing her. We were just rocking slowly, and watching TV, probably one of her Sesame Street videos, I don’t know. We were alone—I don’t know where my husband was.

I was talking to her endlessly, just absently commenting on the action of the video, or singing along with the songs. It’s what they tell you to do, of course—you’re supposed to keep talking and talking to an autistic kid, trying to make some little connection, elicit some tiny response. It came to remind me of how, if your ship is sinking in the middle of a dark empty ocean, you keep sending the flares up anyway, just in case someone else might be out there, invisible to you.

We felt cozy that night: we both liked the Sesame Street videos, and we both liked rocking, and I think it might have been winter outside, because being inside felt more than usually luxurious. I leaned in close to Hannah’s ear, and I whispered, “I love you, Hannah.” And as we kept rocking I added, “Now you say, ‘I love you, Mommy.’” And it was just one of my rituals—I had so many in those days. I didn’t expect a response. I didn’t expect anything. It was just another of those things people told you to do, like waving goodbye when she boarded the pre-school bus, or trying to coax her into blowing out the candles on her birthday cake.

But on this particular night, just like that, as if it were the most everyday thing in the world, Hannah turned her face toward mine and said, very plainly, “I love you, Mommy.”

Or maybe she didn't turn her face. Maybe she just stared into space as she said it. It happened so fast, and it was some twelve, thirteen years ago. I'm not sure I can trust my vision of it. I can't remember the tone of her voice anymore, whether it seemed heartfelt or just mechanical, parrot-like. ('Echolalic'—that was the term they all used.) Just seconds after it happened, in fact, the whole thing fell apart. It began to feel completely unreal, like a scene from one of the thousands of dreams I've had in which Hannah talks.

So by now the only way I know it happened at all is that I made a point of remembering it. I said to myself—right then, as I held Hannah in the chair, and we watched Sesame Street, or whatever it was—I told myself that I'd have to hold on to this moment. It might be the only time I'll ever hear these words, I thought, so I've got to carry them with me forever, and they have to be enough.

“Pink, small, and punctual”

From a letter to a friend, March, 1993:

Tomorrow morning, if all goes according to plan, I'll be going to the hospital for what should be a gentle and gradual induction of labor... I think of today as the last day of a particular sort of life, the last time I'll be able to think of Hannah and me as an integral duo, and of the three of us as “the family.” For several months now Hannah and I have had a ritual of going up to her bed together, and of my lying next to her and singing her to sleep. She likes this so much she's begun asking for it as early as 7:00, when her usual bedtime is 8:30, and generally I've liked it too, although sometimes it takes over an hour before she's finally asleep, and sometimes she gets overtired and cries and cries before she finally nods off. But there's a luxury to these bedtime sessions, a leisure that, after tonight, can't possibly continue... I knew how to have one child...but I don't know how to have two.

Becky was born on March 12, 1993. And with her birth, along with what must be the standard joy, wonder and upheaval, I seemed at least temporarily to gain wisdom—that is, if knowing you're not wise can be considered a form of wisdom:

[Diary entry, June 16, 1993:] One thing I know now is that I can't predict, never could predict, how I'll feel or who I'll be...I can feel myself letting go of the idea of myself as judge and interpreter of my life. I sort of lift my hands and say, “Who knows?” and it's a scary thing, but also sometimes a relief, and at the best times it's even, mainly, interesting.

Becky is three months old, and she's a joy to me—and the joy is sad because it's joy—I mean because suddenly I see what I've been missing all this time. Already there's a connection there, a very deep, very human bond. She looks at me for minutes at a time, she gurgles at me. Yesterday for the first time I made her laugh out loud. Every day I see more and more response.

I don't remember if Hannah did these things. It feels new. I'm trying hard to recall Hannah as a baby. I looked through the photos today, and for all I could tell she looks so

normal—all the smiling, the eye contact and the play. But I don't remember. My feeling now is to wish Hannah had been strange in those days, just so I could take Becky's responses as clear signs she'll be normal. I've looked at the videos but not much—it's still scary and painful.

Hannah ignores Becky, mainly, but shows no malevolence. Occasionally she gives her one of her trademark close-up goofy stares—a sign of affection, I think. And sometimes I end up holding both of them at once, and Hannah tries to make sure that my arm stays around her, that my head stays turned her way. This is the closest thing to jealousy I've seen so far, unless you count the head-banging tantrums. But these come from nowhere, no clear place anyway—I don't know what causes them. They seem to come in phases.

For a week she'll be good-natured, then the next week she'll be volatile, violent, ready to blow. I'm shaky, tense a lot of the time, even though basically life is as under control as it's likely to get—better than I expected. Becky is such a sweet-tempered girl. Not perfect (in that sense) but generally tolerant and sweet. One of the things I don't know anymore is what a baby is supposed to be like. Hannah was so much harder—that much I remember. Hannah never slept—Becky more or less sleeps through till 5 a.m.... Hannah nursed constantly, while Becky nurses only when she's hungry. Becky likes her pacifier, but doesn't seem obsessed with it. She doesn't seem obsessed with anything—not mobiles or ceiling fans or the baby swing or the vacuum cleaner...

I feel guilty because I find myself looking at Hannah and not feeling all the overwhelming love for her I felt just three months ago. It's the scariest, strangest part of all this, that she suddenly seems foreign to me, that I can't seem to love her. I can do things for her, I can pretend, I can hold her. Oh, and I do love her and I do know that sometimes. But I guess it's the contrast—it's a wounded love, full of grief and a pain that keeps evolving—not fading but getting deeper and richer, woven into the fabric of my life. With Becky love is simpler. It's more an outpouring. I don't shield myself from feeling love for Becky the way I do for Hannah, or in fact for anyone else.

The thing is I never used to shield myself from feeling love for Hannah. No, not at all.

Three months ago she was the center of my universe. But now there's Becky, who shows by her presence how very much I'll never get to know about Hannah. It used to be I'd hate to see Hannah with other kids—it was too painful. I'd avoid parks, I'd avoid noticing what the nieces/nephews were doing, not listen to the stories of the cute little things kids say. Now, and forever after this, I'm going to have that reminder all the time—what we've missed. And it'll always—no, I can't say that, really, I have no idea—but for at least a while it'll be a two-edged sword. The wonder of Becky will only make me sorrier for the things I'll miss in Hannah. As I write this, I realize how much I love them both, and how I pity them, and how helpless I feel. This may be the center of motherhood—this helplessness. I wish I could shelter them both from the world, from each other and from themselves, from every harm, but of course I can't.

I wonder now, re-reading this passage, if there were ever times in those days when I felt free to think of Becky as herself, pure and simple—when I wasn't implicitly or explicitly comparing her with Hannah. Maybe this is how it always is with a second child? You can't just look at her whole and separate—you always see her as a member of the larger tribe. She's the newest member, and maybe even the most delightful member, but instead of purely marveling at that you feel guilt, as if every child a mother has is a betrayal of the child who came before. I don't know how people manage large families, though I'm glad they do. I'm unreservedly grateful for my own eight brothers and sisters, though our profusion meant that we each got short shrift, at least from our parents, along the way. I also don't know how much my comparisons of Becky and Hannah were heightened and made more frequent by the fact of Hannah's disability, though certainly that's what made my "joy" so "sad." And the other thing I don't know is how much my constantly feeling torn between the two of them was just me—my eternal tendency to overthink, to second-guess, to feel forever suspicious about my own thoughts, feelings, motives. As must be pretty obvious by now, I have never been very good at just letting life be.

“I watched her face to see which way”

The head-banging was new. Up to that point, Hannah’s placidity was broken only by occasional bouts of pinching, biting, whining—lashing out at others but not at herself. Now, at the age of four, she’d begun to express her frustration, her pain—or, really, what was it she was trying to express? or was she “trying to express” anything at all, and not just hurting so badly that the only release she could find was in self-destruction? —by flinging her head hard against a hard surface, usually the living room wall, but sometimes the kitchen floor, which she seemingly chose because it was the one floor in the house not buffered by carpeting. It was hard to restrain her when she got this way. It would happen quite suddenly, for one thing—she always got in at least a couple of blows before you could get to her and wrench her away. And when you did get hold of her she would try hard to break free, and when she couldn’t (for in those days I was still stronger than she was), she might try ramming her head against you instead. Against *your* head now—if you weren’t agile enough to avoid the blow—presumably because it was your head, now, that was the closest hardest surface in her reach.

I’ve yet to find, in any of the books I’ve read, a consistent explanation for why so many autistic people resort to self-injury. Some “experts” say it’s because they’re feeling under-stimulated by their environment, and that head-banging, hair-pulling, hand-biting (and on and on) are in that circumstance the only ways they know to feel anything at all. Others say they’re sensing *too much*—that their environment is *over*-stimulating them, so they hurt themselves as a distraction, a way of shutting the world out. Some people say that autistic people injure themselves to get attention, to express frustration, or to escape from a task they find onerous. Others say they do it in order to release soothing chemicals in the brain. I myself was never able to come up with any theory at all, though I don’t suppose I ever gave up trying.

There was a CD I used to play a lot—*Walk the Way the Wind Blows* by Kathy Mattea—and Hannah loved it too, and I would sing along with the lyrics, which made both of us happy. However— and it took me an unconscionably long time to figure this out—on the album there’s a particular song (“Song for the Life”), and, really, just one single, high note in that song, that would trigger something in Hannah, make her suddenly anxious, and for just the moment while the note lasted, she might groan, shake, or even make a wind-up move toward banging her head.

Once the note was gone she'd be all right again, and, in fact, with time and repetition, she actually seemed to learn to prepare herself for the note, until eventually it didn't seem to bother her at all.

It's been some time since I've re-listened to "Song for the Life," but today, in a rare display of derring-do, I play it again. It's still a good song, beautifully sung. At first I'm not sure I'll remember the precise note that Hannah found so disturbing—and then, of course, there it is, and it hits me like a quick hard slap. For though it's right on pitch and not too high or unexpected or in a foreign key, the note sends out the same little shock I somehow "learned" to feel twenty years ago. It starts in my ear then jolts through my teeth and jawbone. The pain lasts half a second, maybe, and is merely the result, I guess, of useless, leftover empathy. But here's the bigger surprise: how blessed I feel at this moment, as I discover that, even after all this time, my heart-mind can still feel so viscerally connected to, so complicit with hers. How lucky that such a small thing should retain the power to hurt and haunt me, even as other remnants of those long-gone days have grown, somehow (and intolerably), tolerable.

I mention the song and its high note, because, so far as I can remember, it was the only thing in Hannah's whole world, her whole history, that ever had a clearly predictable negative effect on her. Every other moment with her was a crapshoot; every other moment we simply had to be braced and ready. One second she'd be in a blissed-out trance, rocking steadily in her rocker to the beat of her Sesame Street songs, vocalizing her ecstasy; and then suddenly she'd let out a wail and ram her head, boom, against the armrest. Or else, after a trouble-free visit with the neurologist, during which I might say, as I often did, "Her behavior seems to be getting better these days," Hannah would fling herself against the hospital wall, cratering the plaster, reopening the unhealable gash in the center of her forehead.

This was the start of the medication era. Dr. G had already prescribed amitriptyline—and when that didn't work, trazodone—to help Hannah sleep through the night. Now she added risperidone, and when that didn't work, she took it away and added tegretol. Then Seroquel. Ritalin. Clomipramine. Prozac. The list of things that didn't help—or, more likely, seemed to help at first and then suddenly stopped helping—grew very long. In the meantime, Hannah was fitted for a safety helmet especially designed for self-injurious children. She was supposed to wear the helmet all the time, but Hannah hated it so much—it seemed as much a cause of her

head-banging as a cushion against it—that even her teachers decided just to keep it handy, and put it on her only when her behavior started to “escalate,” as we’d all begun to put it.

By the time she turned five, Hannah was smashing her head against windows, breaking the glass every time—yet always, always remaining physically unscathed—and so, one by one as they broke, we replaced each pane with plexiglas. The walls of our house, meanwhile, were riddled with holes, which for the next eight or ten years we didn’t bother to re-plaster—it seemed so pointless—and in fact, as time went on, it became our sort of standard, black-comic joke when we had company over: that we could measure Hannah’s growth by the height of the holes in the walls.

“I wish I knew that woman’s name”

Diary entry, July 4, 1993:

I watched the fireworks tonight from the library window—the room we call the library, and the window I’d cleaned Hannah’s excrement from the night before. She likes to smear herself, smear things—it’s taken some getting used to, to try to think of it as just another difficulty, nothing so foreign that it removes her from us entirely, removes her from what we think of as human behavior.

The hardest thing is not being able to get in, to interpret or understand. I don’t know Hannah—I who know her better than anyone else. She’s utterly alone in the world. I had a dream once of looking down at her through water, and she could breathe, below the water, and even seemed quite content there, but she wasn’t reachable, and I felt helpless.

I watched the fireworks by myself. Henry was in his room reading, and the kids were asleep. I used to dream about the day when Hannah would like the things I did as a child—the usual things, certain books and movies and amusement park rides. Fireworks. I looked forward to introducing her to those things. Now I have to shift my anticipation to Becky—that might be a healing thing, and I think I can see past the idea that it’s a betrayal of Hannah. But I find myself out of the habit by now of trying to predict a child, and certainly of looking forward to a little girl’s growing up. Often when I look at Becky, there’s a big blank space where her future should be—I mean even the everyday changes. It’s not that I don’t think they’ll happen, but that I don’t imagine them at all. I hardly even ask the questions: Will she talk? Will she be like us? Much less do I consider what she might say, or become.

And yet one worry I have is that she’ll feel burdened by Hannah. Cheated out of a normal family. But of course she won’t be expecting anything different—not the way Henry and I did. Maybe it’ll make her stronger. At the very least she’ll gain a wisdom that I wish I’d had all along. She’ll know—she’ll see it as an ordinary truth—that we all run the risk of being wounded, and that some people aren’t like the rest of us but that’s okay. Maybe even good in some way I can’t seem to fathom right this minute. I hope she’ll be smarter than I am. I think she’s bound to be, whether she wants to or not.

There were good days, always, all along the way, and even in the middle of the bad days there were good moments. As they got older, I let the two girls take baths together every night. Playing in water was one of Hannah's favorite things, all her life, and the two of them had many long, finger-wrinkling good times in the tub. It was the one place they interacted—at least in some small way: I have a dozen photographs of them, Hannah sitting nearest the faucet, and Becky ensconced in her plastic bath ring, its suction cups mooring her to the tub bottom, and they're looking at each other, smiling wide, seeming for all the world like any other two rosy-cheeked, tangle-haired, bonded sisters. Hannah loved to pour water in high arcs, from cup to cup, and Becky loved to watch, then imitate her.

Some summer days when they were both a bit older, and the three of us were going stir-crazy in our daily non-routine routines, I might let out a little cry of frustration and then, without a moment's pause, pack them into the car, buckle their car seats, and drive. Sometimes I'd drive barefoot. Sometimes, if I remember rightly, we were all still in our pajamas. I'd drive us through Dairy Queen, buy them ice cream cones and then keep driving, all around town, or just as often, out into the country and even onto the hilly dirt roads just beyond Butte's western outskirts. Hannah loved the bumps and sudden swerves of those rutted roads, while Becky, even in the midst of bouncing around, often fell asleep, her ice cream half-eaten, melting on her lap. I'd drive for maybe an hour, all told, picking roads—some of them more like trails—at random, and somehow not worrying that one of my routes might end suddenly in a No Trespassing sign, or become so rough that my little Honda might get stuck in a rut or hung up on a rock.

Taking them to parks was harder, partly because we all had to be dressed (at the same time!) for that, and partly because it meant turning Hannah loose, which was always hit or miss. So I generally saved those outings for times when Henry was around to help. Our marriage was as rocky as ever, but sometimes, sitting on a blanket at the park while Becky toddled to and fro—never too far in any direction, always turning around, looking at us, heading back—and Hannah, whooping, swung higher and higher on a playground swing, we could have good, if tentative, conversations of the kind we used to have when we were single. True, it was hard for me to think the way he did anymore—of abstract things, external things—but sometimes I could rise to the occasion if he brought up some very particular subject: a political scandal, a trend in academia, a book he was reading.

“If nobody ever sees who you are,” I remember asking him one day in the park, “do you start to become less real to yourself? Do you start to lose hold of yourself a little, and become more mutable?” It wasn’t the sort of question he could answer well, or even, really, understand, but it was the sort of thing I thought of often these days, when I allowed myself a thought. As I would write in my diary that night:

I have so little of what most people would think of as a real life that I spend hours gnawing away at the bit I am given until it’s gnarled beyond recognition. A phone call to the travel agent, a grocery store trip, a dog entering the yard—I strain to find something interesting in the dullest of events. The cumulative effect of this sort of thing is a kind of intellectual eyestrain, something like the headache you might get if you were carving the Declaration of Independence onto a grain of rice.

“To venerate the simple days”

I had friends in Butte but didn't see them often, and when I did I tended to keep myself to myself—to become, as I put it in my diary, just “that nice person who asks how their vacation went.” I wasn't sure my life would make sense to other people. Eventually, besides Henry, the people I began to feel closest to were Hannah's teachers, Sandi and Tom, or else, increasingly, the growing fleet of Hannah's babysitters.

By the time Hannah was six we had an armada of such caregivers, some of them students recruited from Henry's college classes, plus a few people we called “aides” or “home shadows,” provided by the state, via Family Outreach, specifically to work with Hannah. Amanda, Brandon, Cathy, Christine, Clarissa, Diana, Jackie, Julie, Kari, Kathi, Nicole, Sarah, Sonya, Tara, Val — this over-the-years list of people I owe my life to could go on for quite a while.

Sometimes they worked with Hannah one-on-one, sitting across from her at a kid-sized table trying to get her to follow the simple commands outlined in the ABA (Applied Behavioral Analysis) guidelines. ABA was the teaching system we were all just learning at the time. It's also the only autism intervention I know of that's been proven, in the course of many years and many modifications, to do any lasting, quantifiable good. (ABA didn't end up helping Hannah much, and nobody will ever know why. Yet it haunts me more than any other therapy we tried. It is, of course, my habit to be haunted: ABA could have been our ‘miracle cure,’ I often still suppose, if only we'd been doing it right.)

Or else Hannah's caregiver might drive her to a park or swimming pool, or, once a week, to a family ranch just south of town that provided Butte's version of the “Special Riders” program, in which disabled kids in safety helmets ride gentle horses in wide slow circles within the corral, their guardians jogging in the dirt alongside them. (It was around this time that I first faced the fact that even an ancient mule plods faster than I can run.) The idea behind “Special Riders” is that autistic children may relate better to animals than they do to human beings. (It's the same idea behind Dolphin Therapy, except that a day at Dolphin Camp costs over \$2000, whereas the Kissonick Horse Center provides its “hippotherapy” for the cheerier price of ‘free.’)

We never saw signs of any special equinological connection between Hannah and her horse.

Still, I'm prone to believe that she bonded with him a bit more personally than she had with, say, the toddler-sized plastic rocking horse she'd long outgrown at home. Whatever the case, on a good day she liked the riding very well. (And on a bad day, she really, really didn't.) I think it was the bump-bump-bump of it that soothed her, the up-and-down, the traveling in circles, and, maybe more than anything else, the view she had from her saddle-perch, so high above us all.

Oh, how Hannah loved high places. The tops of cabinets and doors. Banisters, railings, ladders. The apogee of her swing's arc, or a huge, high bounce on a trampoline. Or else—whenever I turned my back, it seemed—she might climb out an upstairs window to the sloping roof of our front porch, then hop about out there like a preacher whooping the gospel. To an untrained audience, this performance was often unnerving. Sometimes, in fact, I would learn that Hannah was on the roof again mainly via the helpful, frantic honking of the cars coming up our street.

I remember something else now: how, like a sailor in a crow's nest, Hannah liked to linger on the platform atop a playground slide. At first she'd whoop in lusty glee at—what?—the dizziness, the shift in perspective, the way we all looked so delightfully small? And then she might gaze silently outward, all around, with one hand pulling at the corner of her eyelid, so as to blur or, maybe, vivify the panorama, and the other hand keeping a casual grip on the curved iron railing. She looked for all the world as enthralled as Balboa must have felt when the natives first showed him the Pacific Ocean.

In Hannah's case, of course, there was often a ladderful of other kids lined up behind her, waiting with touching patience for my daughter to go *down* the slide already so they could have their turn. Those who knew Hannah a little would soon just sidle their way past her, and she'd allow that, she'd make room. Those who didn't know her—well, they simply *got* to know her, and quickly, sweetly, for the most part. Hannah rarely engaged with other children, rarely even glanced their way. (I believe she realized early in life that adults were far more useful.) And perhaps it was because she didn't notice them that children found her so safely fascinating. Some of them would speak to her, especially once they learned her name, and thus had something to say: "Hi, Hannah." "How do you like the slide, Hannah?" "Watch me, Hannah—wheeeee." Her lack of response was okay with the kids, and maybe even made their interactions easier, more clearcut. And this would be the way of things, pretty much, for the rest of Hannah's life—kids were often drawn to her, and many wanted to bond with her somehow, get her to speak or nod or

meet their eyes. They wanted to hand her a cookie, tie her shoes, lead her in or out of a classroom. We met them sometimes in grocery stores or at the mall: sweet, neurotypical kids who knew her from schoolyards and called out, “Hey, Hannah!” even before seeing us, just from having heard her whine or whoop from an adjacent aisle.

We were lucky: all her life, nearly everyone who met Hannah wanted to help her, teach her, make her happy. Unlucky too, I suppose, for I seldom met anyone who could do much to help her for real. One of the sweetest, saddest things our “home shadows” had in common was that nearly all of them, when they first came to the job, were very sure that *they* were going to be the one to facilitate the miracle. “I just think God has sent me here for a purpose,” one said to me once, and I could see it in her eyes, as I would see in many others over the years—that beautiful, doomed, messianic impulse. It would last a few months—even longer in the hardest among them—before it would fade, bit by bit, or, in a couple of cases, flame out suddenly and completely, so that, heartbroken, some shadows couldn’t bring themselves to do the job at all anymore.

But the ones who went the dangerous distance were heroes. Among them: Kaitlyn, whose thumb Hannah broke as they waited in the Burger King drive-through lane; Christine, who suffered nerve damage when Hannah bit her hard on the neck; Amanda, who helped me hold my daughter still, on a hospital bed, as the enema the nurses had given to relieve Hannah’s constipation achieved its most explosive effects; Brandon, who knocked at her bedroom one morning to get her ready for school, and found that, sometime during the night, Hannah had died.

(Ah, but that last thing hasn’t happened yet. I have time—don’t I? I have a few more chapters before I have to re-know that part.)

There were a few really lousy home shadows as well. The one who occasionally stole my clothes. (She once showed up wearing one of my favorite sweaters, right in front of me—and, no, I couldn’t bring myself to mention it.) The one who made us pay a thousand dollars to repair (what seemed to us to be) a tiny dent that Hannah, in one of her rages, had put in the hood of her husband’s pickup truck. Another woman left Hannah alone in a park for half an hour while she went to visit a friend who lived across the street (she could see Hannah from the friend’s window, she assured me afterwards). Worst, by far, was an aide Family Outreach found once: he

never seemed quite “right” from the start—eye-avoiding, uninterested. Then after a couple of months I was checking the cable bill and learned that he’d been using his afternoons with Hannah to rent pay-per-view porn on our TV.

Even so, even so, we were lucky. Sometimes two people worked for me at once—one each for Becky and Hannah, while, at other times, one aide might care for both girls together. This meant I could retreat to my office some afternoons and try, however fitfully, to write. It also meant Henry and Becky and I could go to people’s houses without Hannah sometimes—without the worry that Hannah might destroy something there or fall into a sudden rage. It would have been impossible otherwise: witness the year the four of us went to another family’s house for Thanksgiving dinner—the sort of occasion it’s impossible to get a sitter for—and Henry and I spent the day taking turns sitting in our friends’ basement laundry room with Hannah, trying to keep her the least bit interested in bouncing a ball, while the other one, upstairs, used that furtive opportunity to gulp down dinner.

Having help also meant that Henry and I could go out by ourselves together some nights, and to try, in this way, to retain some semblance of a one-to-one relationship with each other. We’d play darts or pool at a bar or, during one of Henry’s months-long stretches of alcoholic abstinence, we hung out at a local coffeehouse that catered mostly to college students. We’d bring a Scrabble board or a deck of cards, and we’d while away two or three hours there, just him and me. And though our everyday dealings these days kept growing tenser, more volatile—our marriage staggering up love’s canyon like an overloaded mule—our conversations during our evenings out were mostly affable, relaxed, the way we liked to think “the old days” had been. Afterwards, the weight of heading back was always heavy, and we stumbled beneath it, all the way home.

“’Twas such a little, little boat”

I was pregnant with Becky when I first met Ben. It happened—the meeting, not the pregnancy—in a Marriott Hotel in San Diego, in the summer of 1991, on a weekend where I met so many fine people that it’s rather rude of me, I think, to single just *him* out from among them all. What a heady experience: my first National Puzzler’s League (NPL) convention. My first nights (three of them!) away from Hannah, too. (I may be the one person ever to attend an NPL convention with the goal of catching up on her sleep.) I spent the first day of the event with my arms folded against my engorged breasts, in case milk soaked through my peasant blouse.

Despite how I long to, I won’t write for days about my love of puzzles. May it suffice that as a kid, I knelt alongside my family in church, for all the world a fledgling saint, and turned the pages of my Saint Joseph Children’s Missal with the silent intensity of a little girl caught in the ecstasy of rearranging hymn numbers into mathematical equations, noting the various ways one could spell “hallelujah,” or anagramming words in the Apostles’ Creed. (“Everlasting” = “strange evil.” “Pontius Pilate” = “tailpipe snout.”)

Meeting the puzzlers was like returning, for the first time, to my home planet. I’m not the first one of us to say this, of course—it’s almost an NPL catchphrase. (We should put it on t-shirts.) In the giddiness of being encircled by so many brilliant, delightful people--“kindred spirits,” as I think of them--I suppose I could have fallen in love with *anyone* that weekend. But I think myself lucky in falling for Ben. He was gentle, for one thing—preternaturally so—and unimpeachably amiable. He made crosswords for a living, so his mind whirled with creativity, while mine, at least in those days, merely whirled. He was loyal and strong and brave. He had a great mustache. He was also, as it turned out, completely unattainable: a bachelor who has lived alone forever (have I *ever* lived alone?) and very much likes it that way.

Diary entry, August 13, 1991:

After the night’s official games, [Ben] invited me to solve a cryptic crossword with him, which in the NPL is the equivalent of a marriage proposal, or so I prefer to imagine. That evening, in a bedroom-sized conference room, we sat alone at a long table, and by the light of a spookily tarantulous chandelier, we co-solved our first puzzle. He pulled his chair close beside me, and—oh—he had to know it, I thought. He had to feel the way our

arms, our thighs aligned with each other, pressed together, without a hint of pardon-me withdrawal. We collaborated wordlessly within this brazen touch, this purposeful pressure of my right side against his left. True, we had to lean our heads in close so we could read from the sheet of clues that lay between us, but our thighs had no such excuse whatsoever. Yet there they lingered. This wasn't how other puzzlers co-solved.

The bathos infusing this paragraph, no matter its self-awareness, should surely embarrass me far more than it actually does. But wait, I go on:

The convention wrapped up late Sunday morning, and the crowd of us—how amazing to have found so much new family in one weekend—were in the lobby, checking out, waiting for cabs, chattering, hugging, saying goodbyes. Ben and I found a little time then, semi-alone in an alcove, to say a more private goodbye. I hadn't slept with him, of course, and not merely because he hadn't asked me to. Truly, it never seriously crossed my mind that I would. I'm married, for one thing—to a brave man who was probably, right at the moment of my most feverish longing for Ben, trying to lull Hannah to sleep sans the superpower of lactation. I was also--a fact I didn't share with the conventioners--ten weeks pregnant with Becky.

Still, still, there's something there, I know it. We hugged each other in that alcove, two three four times, then once again for luck. I pretended to straighten his shirt collar. "So," I said, "you'll write me every day."

"Oh, twice a day," he answered. We laughed.

"And you won't think of anyone else but me?"

"How could I?" he said, laughing again.

We—both of us, I realize now, and not just Ben--were only playing a game that first weekend. Nonetheless, as the decades have confirmed, it was a game we'd both always longed to play, a game we were naturally good at. And we'd found in each other, at last, a partner who seemed to know the fairy-tale rules.

Thus, my first move toward infidelity took place only in my mind, as all through the year that followed, and then on and on, for several more years and beyond all reason, I began to think of

Ben continuously, in one long, rarely broken train of thought. We talked casually on the phone, wrote a few postcards here and there, but it would be another three years before I had another moment alone with him. Meanwhile, back in Butte-Montana-of-all-places, I found myself having conversations with Ben in my head, and it wasn't long before he was virtually *there* with me, all the time: a wry hallucination in my living room as I trimmed Hannah's bangs, an invisible companion during my drives into the countryside with both kids, a figment who appreciated my internalized gallows-humor commentary as, for the third time in a day, I led Hannah to the shower to rinse feces from her arms, chest, and legs. In bed beside Hannah at night, I'd turn my pillow sideways and cling to it, pressing my head downward, as if straining to hear Ben's phantom heartbeat.

I understand well, as I did at the time, how small and pathetic my fantasy was, especially as over the months and years it grew more and more elaborate and all-consuming. Rocking Becky toward a nap, I became, instead, a nightclub singer crooning "What'll I Do?" to a hushed audience in which Ben sat, enraptured, at a front-and-center table. Folding laundry, I had long, half-aloud conversations with him, interrupting them mid-sentence to edit the dialogue so that each of us could sound more clever and romantic than anyone could ever possibly be in real life. In the dreamworld I was blithely famous, and Ben and I lived together in his home in Valhalla. (No joke--that's actually the name of the town. It's in upstate New York.) Henry had already left me for someone else, it didn't matter who, so I was conveniently guiltless, and in fact I hardly even thought about him. My two little girls, as well, were present only now and then, and vaguely. Meanwhile, Ben and I floated through various scenarios, some glamorous, and some—the more satisfying ones, somehow—more everyday. I even invented scenes in which we argued—usually about my single-minded devotion to my music career, I believe. Once, in a restless mood, I took us through a two- or three-month storyline in which, feeling neglected, he cheated on me with an old girlfriend, and I had an imaginary affair with another puzzler I found swoon-worthy. Eventually, of course, Ben and I reunited, melting together into an ardent, perfectly worded denouement.

“The moon is distant from the sea”

Meanwhile, back in real life, we muddled along. We came to the end of the 1995-96 school year, which was also the end of our time with Tom and Sandi. And as with every transition we faced along the way, that goodbye was poignant, our next move frightening. In September, seven-year-old Hannah transferred into our neighborhood elementary school, where she was “mainstreamed” into a regular first grade, with, more or less, just her one-to-one aide—her “shadow”—along to support her through the day. Mainstreaming was a popular concept at the time (and remains, I think, the officially preferred placement for students who can manage it), the idea being that isolating disabled children in self-contained classes is hard on their self-esteem, hinders them in developing social skills, and keeps them from reaching their full academic potential. The thinking is also that classroom inclusivity will teach NT (neurotypical) kids that people with disabilities actually exist, and they should get used to it already.

I myself came to the concept with an open mind but my usual fretful heart. I visited Hannah’s new classroom every day during her first couple of weeks there, and it was painful to watch her shadow’s vain efforts just to hold Hannah in place at her desk among the others, much less to get her to pay attention to anything the teacher might be saying and doing at the front of the room. And even when Hannah sat, she didn’t sit still. Even in a good mood, she’d rock her desk back and forth and chant her exuberant sing-song. By the end of the first week, someone brought over the padded rocker they’d had in place for her in Sandi’s classroom, and installed it in its own padded corner at the back of the room. Afterwards, Hannah spent a lot of her time back there, which was not quite so disruptive to the rest of the class, but which I don’t suppose did *her* much good. (Nor, for that matter, did it help the “regular” students get past thinking of disabled people the way the citizens of Maycomb thought of Boo Radley.) Hannah would rock and chant and pay no attention to the world around her, while her shadow sat in a straight-back chair beside her, braced for the rage that might erupt from her at any time.

The shadow was new, and a man this time. It had taken all summer and three weeks into the fall to come up with him—this was becoming a job most people weren’t eager to take. His name (let’s say) was Tony, and he was small, wiry, and had the old-time, grizzled face of a boxcar hobo. And that in itself was quite all right—the grizzled look is popular in these parts. Like previous shadows, Tony had no particular credentials or experience with disabled children, and

that was all right too. No, my real worry was that he didn't seem particularly intuitive, attentive, or even, frankly, all that bright. And I felt a bit uncomfortable that he should be the one leading the charge toward a major goal for us that year: Hannah's toilet training. (In the end, a female aide from another classroom handled most of that.)

But Hannah took to Tony right away--in part, I suppose, because she always had an exceptional fondness for men. Men were exotic. Hannah loved to lean in close to them and smell what must have seemed a dusky foreignness; to leap into their laps as if they were big, indestructible toys; and, especially, to run her face or fingers through a beard or mustache or, even more thrilling, across the prickly stubble on a beardless man's face. And in part, I think, Hannah liked Tony because he didn't demand much of her. Instead, he was her stolid, largely silent companion, who might steer her toward classroom activities, but very rarely coaxed her to perform one. Now and then, in fact, I would drive up to the school to find the two of them outside, alone, strolling the perimeter of the playground--Hannah bouncing, jabbering, and Tony alongside her, contentedly smoking a cigarette. It was what they would do when Hannah couldn't sit still anymore, or when she needed a change of environment after a bout of rage, and the pair of them looked comfortable together, aimlessly circling the playground, spellbound by their separate, private visions.

Sometimes Hannah would come home carrying a worksheet or art project that was so perfectly pasted or cut or colored-inside-the-lines that I knew it must be Tony's work, and Henry and I would joke ruefully that at least *one* of them was getting an education. As we'd all reminded him on various occasions, Tony was supposed to be working with Hannah, hand-over-hand, on these sorts of things. Yet day after day, these painstaking pages came home in her backpack--each letter round and proper, each crayon stroke inside the lines, and Hannah's name spelled proudly (if missing its final "H") at the top of each page. (I once asked Tony, as he handed me another perfect worksheet, "Are you sure you don't want to hang this on *your* refrigerator?") And on it went, and after a while the papers became symbols, for me, of how dismally the year was going.

Imagine my delight, then, when one day Hannah brought home a ragged, twelve-by-eighteen sheet of butcher paper that she'd bombarded with multi-colored, madwoman scrawls that once or twice tore right through the paper. I framed that picture; I hung it on my office wall. Even today I smile to look at it, in part because its intensity and vibrancy make it seem a self-portrait, and in

part because, below Hannah's shrieks of color, Tony had penciled in his own, triumphant caption: "9/26/96. Hanna did this by Herself. She did not Eat any Crayons." The school kept a journal of Hannah's ups and downs, and every day they sent it home with her. The reports, written sometimes by the teacher and sometimes by Tony (or, more and more often, his substitute), varied widely:

"Good until 10:45, then she bit her left hand and sat and whined."

"Took Hannah to wash her hands and she asked to go potty. Crackers for a snack and Hannah asked for her crackers very clear. Very good morning."

"A lot of pinching, refused to do anything. While waiting for the bus she started to bang her head on the wall."

"She dumped a bottle of glue and tried to eat it. When told no, she turned and bit me on the leg."

"Hannah was fine until about 12:40 when she threw a tantrum. She grabbed her chair and banged it up and down. She then banged her head off the floor. Fine until 1:30, then threw another tantrum."

"Hannah had a pretty good day. She crawled on my lap and was very affectionate."

"Took her to brush her teeth and she ran back into the cafeteria and helped herself to someone else's lunch."

And so on—up and down, up and down, with hardly a day that was purely good or bad.

The last time I saw Tony was on a weekend afternoon in the spring of 1997, when he stopped by the house to ask me to lend him forty dollars. He needed to buy quinine, he said, to fight off a recurrence of his old malaria. "Oh, my," I said, and gave him the money. The following Monday he didn't show up to school, and that was, at least for our purposes, the end of him. For several weeks after that, the district managed to bring in substitute aides, or, on days they couldn't find anyone, asked me to keep Hannah at home.

This wasn't right, I knew. Indeed, nothing in the past several months had been right—not mainstreaming, not Tony, not the lack of any discernible progress, not the dozens of times they'd

called me to come pick Hannah up early because they couldn't deal with her themselves. It was becoming clear that despite all the care, planning, meticulous detailing of goals and objectives laid out by Hannah's "child study team"—that earnest group of teachers, therapists, social workers, psychologists who, without a doubt, were all doing the best they knew how—Hannah was going nowhere these days.

But, really, when I allowed myself to think about it, had she ever been going anywhere, even in the relatively untroubled Tom-and-Sandi days? Hours of speech therapy every week for those three years, yet she still hardly said a distinguishable word. Instead she made occasional guttural requests to get things she wanted, at the end of which, after months of repetition, they had finally taught her to add the word "please." (It came out as "peas.") The victorious upshot of this was that nowadays she might be diving across the lunchroom table, lunging for your cheeseburger like the wolf on the fold, but she was always very polite about it.

True, there were several breathtaking moments of clarity, over the years, which, like her saying "I love you, Mommy" as I rocked her that long-ago night, came, in time, to gather the inspirational power of myth. Tom the speech therapist liked to talk about the time Hannah grabbed up strips of construction paper and suddenly began rattling off their colors—blue, red, purple, green, yellow, orange—just like that. Another teacher bore witness as Hannah looked out the classroom window and, as one of her aides approached from the parking lot, called out cheerfully, "Here comes Jeannie!" Someone else told a tale of Hannah looking down at the carton of milk she'd just spilled across the table and announcing, clear as day, "What a mess!"

But there was nothing we could do with these rare moments, and little we could say except to repeat their shimmering details to one another, like disciples reaffirming the miracles of Jesus. Meanwhile, Hannah's everyday speech remained garbled and minimal.

Still, there was at least one huge success during this otherwise fallow period: Hannah's caregivers were making great progress with her toilet training, and in fact by the time Hannah was ten years old, she was reasonably consistent in going to the bathroom on her own. This achievement was—and remains—astounding to me: it was, I think now, the biggest gesture toward artificially imposed, "civilized" human behavior that my daughter ever made. For years afterward, I would often think that if Hannah could surrender to the habit of using a toilet, well

then she might be capable of all kinds of social accommodations. Yet it never would have happened if her aides and teachers hadn't worked so hard on it. On my own, in my perpetual languor and exhaustion and dread of warfare, I myself might have gone on diapering her forever.

“What mystery pervades a well!”

It was around this time—1995—that Hannah began to have epileptic seizures. Something like one in three autistic children suffer them, although, as with more or less everything to do with autism, nobody’s sure just why. Hannah’s first seizures happened at school, so for a while I didn’t quite believe they were real.

After all, her teachers were always finding something wrong—some physical symptom of something or other that they thought might explain a particularly bad day. In the backpack journal, there would often be a comment that, say, Hannah’s bowels seemed too loose, or else, on another day, that she seemed constipated. Her shoes seemed too small, or, a week later, too big. She was “tugging at her ears.” She seemed “not to be getting enough to eat at home.” She “acted like her mouth or her teeth hurt.” She seemed to be limping—“perhaps she’s sprained her ankle?” “She got a bloody nose at recess—why?”

I was forever hauling Hannah to the pediatrician, or, if her teachers’ warnings seemed particularly urgent, the hospital emergency room, and so far the only trouble that had ever turned out to be real was when Hannah had stuffed a bead, perhaps, or a bit of crayon, or a soupçon of play-doh, up her nose.

Putting things up her nose was, for several years, one of Hannah’s favorite pastimes, which I find myself remembering now with a sudden nostalgic fondness. (It was hell at the time, I suppose—but for now I’ll leave it to Henry to recall it that way. It’s as if we’ve signed up for these yin yang roles—skeptic and naïf, worrier and non-resister, agonist and ecstasist.) It might take an hour, with three or four people—me, Henry, and a couple of nurses—trying to hold Hannah still as the ER doctor attempted, with long narrow tweezers, to remove the obstruction. Lots of failed maneuvers, lots of holding our collective breath, lots of just-missed-it moments, and then, when the thing was finally, suddenly out—huzzah!—we all exhaled at once with a colossal sense of relief and triumph, and the sort of wordless camaraderie that soldiers must feel after battle. And then we all leaned in to see—it was always so very important that we know—what the little thing was that had caused all the trouble. Once, I remember with a kind of residual awe, it was a tiny red firetruck.

Meanwhile, I remained skeptical about the seizures. I suppose I knew, deep down, that the teachers weren't just making them up, but I held on to my disbelief for as long as I could. Then, on September 25, 1995, as I wrote in an email to my sister:

I went with Becky to Hannah's school yesterday. She was having a hard day—there have been so many lately—and then I got to witness my first seizure. It was a mild one. She just sort of spaced out, began to tremble, didn't move, got very quiet. We lay her on the floor and tried to say comforting words while we waited it out. Then afterwards (it lasted maybe twenty or thirty seconds) she was tired but not feeling bad, and in a few minutes she was asking for M&Ms.

We consulted the neurologist—not Dr. G but Dr. W, to whom (for no good reason, as it turned out) we'd recently transferred Hannah's care—and soon enough found an adequate medication and an appropriate dosage, so that within a few months the seizures were basically under control, with one or two “slipping through” now and then, as Dr. W liked to put it. This was to be expected, he assured us, and nothing to worry about.

By then, of course, we were all on medications—we were a pharmacist's dream, Hannah and Henry and me. I took Prozac, Henry took Wellbutrin, and Hannah was tried on a thousand things, one after another, each of which raised our hopes and dashed them, in what only in retrospect can I see was a predictable cycle.

I'll let my diaries and letters tell the story:

August 10, 1995: Hannah's doing well on the new medication. It's nearly stopped her rages, which were getting so bad there for the last few months. She's better able to pay attention to people, and even to communicate, and—the main thing—she's much happier.

August 20: Hannah's had some tough days. She's having one right now, in fact, and I've tried about six times to help but she seems inconsolable so I'm just trying to endure it, same as she is. When she's like this the whole house shakes, literally and figuratively. No wonder my marriage is on the verge of collapse.

September 1: Hannah's out of the tub, Becky's down with Henry, and all, for the moment, is right with the world. I can't believe how much easier it is to survive life here now that

Hannah's feeling better. Two whole days without any head-banging at all. It feels miraculous. For a while there I was starting to think pretty direly, wondering if I could even keep her at home should this keep up, if I'd have to send her away someplace (I have no idea where) in order to keep the rest of the family intact. But the last couple of days have been just fine. So I can breathe again, for a while at least.

October 7: Here it is, only nine p.m. and both kids are asleep, and without a lot of trouble from either of them. Plus they took a pleasant little bath together tonight and it was lovely just to watch them interact—Becky doling out foam soap to Hannah, telling Hannah to hold out her hand for it and Hannah actually doing it, and both of them looking right into each other's eyes, and the love you could see on both sides. It was absolutely perfect, the sort of moment that makes me wonder why I don't devote every minute to watching these two in wonder and joy, why I so often just want to get out, even if it's only in my mind, even if it's just to read the newspaper or do the dishes.

November 19: I'm writing this at one of the lowest moments I've had lately. Hannah's in her room, still raging after a day when the rages never seemed to cease. Becky's asleep on the living room chair, exhausted by a day that began at 4:30 a.m., and an evening where she couldn't have my comfort because I was too busy cleaning up a huge mess of Hannah's—her second smearing episode of the day, and it was everywhere, everywhere. And I was cleaning it up while Becky cried for me to notice her, wanted me to sit with her the way at any given moment these days she wants me to sit with her, nurse her, watch her, don't move, don't read, don't talk on the phone, don't go to the bathroom. And meanwhile I'm trying so hard not to fall apart, but there's this rage, and it comes out in these animal screams now and then, which just upset Becky all the more, but there's nothing to be done except to tell her I'm sad, I'm sorry, I'm not mad at her, and then when finally I sit with her to tell her I love her so much, I hear her answer back, "I love you too mommy," which is the best solace I could have, and the only solace I'm likely to get tonight.

December 14: Three days straight without a bout of rage, and the whole house seems brighter. Tonight the four of us went to the mall—this would have been unthinkable a few days ago—and both kids had a wonderful time. Hannah mostly hung out around the

fountain, staring into the waterfall, listening to the roar. She got so excited she kept running back and forth, sometimes rushing up to strangers and grabbing their hands in glee. The security guard stood off sheepishly to the side, reluctant to tell me that such things weren't allowed. Finally he did, but we'd been there an hour and a half by then and we were ready to go home, so I told him not to feel too bad about it. Now Hannah's in bed, Becky's asleep, and it's only nine o'clock.

Christmas Day, 1995: It was a very good day here. Hannah was in an exuberant mood, and even when we went to a friend's house for a waffle/ham brunch, she didn't get into much trouble, sat pretty well, and even socialized with the other guests (i.e., took food off their plates, smelled it, put it back).

January 6, 1996: This, I think, is about the hardest sustained bad time Hannah has ever had—months now of misery and frustration. I thought the new medicine (tegretol) might do some good, but after a promising start it doesn't seem to be making a difference. Well, at least I haven't seen any seizures (but maybe I just miss them?). I just feel so helpless, and in such need of escape. This is the hardest time this family's been through, and I suppose that's why I've been thinking so much about running away. I feel a bit more in control today. I'm slowing life down a little, putting things off—like the novel—while I take as much time with my kids, and with Henry, as I can. It's a tough thing, balancing it all... Becky seems to be coping very well, and I'm managing to give her a lot of attention—especially while Hannah's at school—and she seems to be doing fine. Becky's such a blessing through all this. "You don't talk about her much," Ben said on the phone last night, and I told him it was because it would be like trying to describe a sunrise, that there's just no way to do it justice, to keep from sounding trite. But she's the best thing ever to have happened to me, and I never stop feeling awed and grateful.

January 19: Hannah's been so wonderful lately, since getting on the Prozac. She's happy almost all day long—just the usual little fits when she doesn't get her way, but those are almost good to see, since I think I'd worry if absolutely nothing ever bothered her... So life is surprisingly calm in this house, and has been for almost enough time for me to actually to get used to it, and even to have a bit of faith that it might stay that way a while.

February 1: I hear Tara [our sitter] downstairs, getting ready to take both girls for a walk. Such ambition. Hannah's had a tough morning, and now and then the house quivers with her head-banging. Yet I sit here, thinking about going down, relieving Tara, but not doing it. I simply can't think of anything more I can do—Tara's idea of a walk sounds as good an idea as any I've had all day. I gave Hannah medicine, gave her a bath, covered her with anti-itch lotion, fed her, played videos, gave her play-doh. So I'm sitting up here, locked in my study, abdicating to Tara.

There are times when I just lock out all the pain of it. Hannah can be banging her head, reeling in her misery, and I just stare. I do what I can, and then I just stare at her, and I don't feel anything, neither anger nor compassion. I think the Prozac helps me pull away—for better and worse. Yesterday she smeared her excrement all over the bedroom sheets, blankets, dresser, walls—the fifth or sixth time she's done that in the last few days—and I just put her in the shower, cleaned her up, cleaned up the mess, all the while calm and even sweet to her. Then about half an hour later I found her downstairs covered in finger-paint—it was my fault, I'd forgot I'd left it out—and again it was on the carpet, chairs, walls, table. But it didn't faze me—I took off her clothes and mine, and carried her up to the tub, where we both rinsed off again.

There are still times when the stress of all this—every day there's some sort of incident, even as we work and work to anticipate and prevent every type of problem—when the stress gets to me, and that's bad for everybody. Hannah gets even more upset. Becky gets hysterical, and doesn't trust me for hours after I've been stomping around, letting out little screams now and then, cleaning Hannah up too vigorously, in a fury of scrubbing. But that doesn't happen so often anymore. Still, at the same time, and maybe paradoxically, I feel more selfish. I haven't put all this together yet, and I don't know what it all means.

“A wounded deer leaps highest”

As Hannah turned eight, then nine, I was continually bumping up against the fact that the progress she was making at home and at school was minimal, at best, and that her bouts of rage and misery were getting worse and worse. At the same time, I was doing all I could—gobbling Prozac, hiring more babysitters, running away to puzzle conventions and crossword tournaments, retreating deep into the make-believe world of Ben—to keep that thought from hitting home.

I fostered the same battered hope that had always been there, deep down, from the early days of her diagnosis: that someday soon an “expert” would appear—someone who would swoop in like Superman and lead Hannah unswervingly toward, if not a cure (for I hardly ever allowed myself quite that degree of magical thinking), then at least some degree of progress, at least some alleviation of her everyday pain. My yearning sprang naturally from a deep and increasingly desperate compassion, but it was also self-serving. It was a way to avoid the plain fact that nobody—nobody here, anyway, and maybe nobody anywhere—had a clue as to what Hannah needed, and that if anyone was going to leap in and save the day, well, it would have to be I myself, wouldn’t it?

Try as I might (try as I still do, sometimes) to dodge the logic of this conclusion, it hit me harder every day. I was the one who knew Hannah best. And I was the one who loved her the most. Moreover, I was really, really smart, wasn’t I? Surely I could comprehend, sort through, put into practice the many theories and treatments bandied about in all the books, newsletters, conferences, support groups, *Newsweek* cover stories. Surely I could *invent*, from whole cloth if need be, some precise, scientific method that would make Hannah learn how to talk to us—or, far more urgent at this point, to make her pain go away. All I lacked, it seemed to me, was that essential thing: stamina. My attempts to find treatments for Hannah were always sporadic, timid, halfhearted—encumbered partly by skepticism but mostly by fatigue, plus an ever-growing longing for escape.

And that’s where the Prozac came in, and I found myself gradually letting it take me over. My doctor prescribed it in the spring of 1995, in an attempt to alleviate what I thought was a severe case of premenstrual syndrome. I’d never put much stock in drugs before, at least when it came

to making *myself* feel better, and I didn't expect much from this one either. But, almost from the get-go, Prozac's effect was life-changing. As I would later sum things up in a letter to my sister:

It's done wonders for me, completely obliterated my chocolate craving and made me so happy it's a wonder anyone can stand me. I've lost some thirty pounds since starting it a few months ago. Very few side effects—well, I was headachey and dizzy and nauseated for a while there at the start, and I absolutely never need to sleep anymore, and it took me a while to adjust to what's essentially a new personality...

And it seemed I *was* a new person. I couldn't write, for one thing—couldn't (and didn't at all want to) find the depth of introspection it takes to be a writer. I was also—and quite suddenly, it seemed to me—imperturbable. Everything that broke was just one less thing to worry about breaking in the future. Hannah's messes merely gave me outlets for my newfound, inexhaustible energy. I remember times I spent happily in the upstairs hallway, cleaning shit from the walls with my bucket and rag, and meanwhile singing a lusty medley of show tunes—mostly the Gershwins, with an occasional nod to Cole Porter.

After several weeks on the drug, I noticed myself becoming one of those people whom I'd never been able to understand before: the sort who “forgets to eat.” I'd always thought, before, that those people were simply making that up, that it was a kind of showing off. But now, thanks to Prozac, I understood completely. Energy flowed from me so freely that I began to look for ways to let it out. When Henry and I played tennis, I found myself looking forward to a badly hit ball going over the fence. “I'll get it,” I'd call out in a musical voice, loping toward the gate.

This is how animals must feel, I thought: most natural, most themselves, while in motion, their bodies as easily accessible as their minds—and, in my case, more so. I needed very little sleep at night. Instead I would lie awake, thoughts racing. My fantasy-romance with Ben took its highest flights in my mind, and especially as I kept losing weight, thus becoming more conventionally “attractive” than I'd ever been before, I drifted further and further toward the idea of somehow making it real. “I have this longing, for adventure, romance,” I wrote in my diary. “I can't seem to shake it, no matter how reasonable I try to be. It's as if, now that I have this new body, I feel the urge to put it to interesting use.”

I was still a pretty good mother, I guess. I spent as much time with my daughters as ever—and possibly more, since it was all so suddenly doable—and I attended school meetings, brought Hannah to doctors and therapists, made sure, as much as possible, that everyone in the house was clothed, fed, entertained, loved. I just did it all in mini-skirts now. Moreover, I felt different. I felt an odd kind of distance from my life, as if I were merely playing the parts of “mother,” “wife,” “friend.” There was a superficiality to me now that I was, at least, still deep enough to notice:

July 18, 1996: *God, I'm so vapid lately. And you know, it feels like it's the only thing that keeps me going sometimes—just total shallow, narcissistic self-obsession.*

Or perhaps—I often felt this way—I was only *pretending* to notice myself: I was playing the *role* of a thoughtful, responsible person. From a letter to a friend:

I worry that the Prozac has made me self-centered and vain. Sometimes I feel sure that it has, and yet I can't get myself to feel even very guilty or regretful about that, because that's the whole point—I want to be this happy from now until forever, and often it seems I don't care what gets lost in the process, or even who gets slighted... I've been selfless for so long... I don't know, what do I deserve now? I want to do right by everyone, especially my kids, but I want to have my own life too. I want to see people I like, to travel when I need to get away, to spend time alone, to get back to work... Can I do all that and still be a good wife and mother?

Yes, I wrote those things. But I'm not sure I really felt the way I felt. So many of my letters to sisters and other friends during those crazy months go overboard with self-analysis, especially as, in time, I found myself moving, with an unswervability that I kept denying to them and maybe even to myself, toward an actual, real-life love affair. “Not that anything's going to happen,” I'd tell them all, in letter after letter. And yet:

August 7, 1996: *The trick is not to want things anymore. I can do that with chocolate, at least, but I haven't found the drug to stave off this other, deeper longing. If anything, Prozac seems to have increased my yearning for other, non-caloric but still dangerous, things, by showing me the possibilities, by freeing me of all that under-confidence, by turning me into, of all dire things, an extrovert.*

“Bereaved of all, I went abroad”

Ben lives a half-hour’s drive from New York City, in that upscale little commuter town so aptly named Valhalla (after the majestic “hall of the slain” that awaited Old Norse warriors). Driving there for the first time, from Henry’s parents’ house in Queens, in the summer of 1995, I laughed again as I noted the exit sign. How delightfully presumptuous to call a town “Valhalla.” And yet it fits. Not that I thought of myself as a fallen warrior—not quite *yet*, anyway, in 1995. But I did recognize, from the very start, that Ben’s world might serve for me as a muted, cordoned-off alcove of heaven.

You had to climb two tiers of steep stone steps to reach the front door. The house itself was otherwise like most others on the block—stately and placid, timber-framed, its lawn well-trimmed, its canopy of tall trees in full leaf. I pulled to the curb and sat there in Henry’s father’s car for half a minute before making my ascent. After all, I was already three years into a meticulously torrid daydream about a man I was about to meet in person for maybe the fourth or fifth, smallish time. For though we’d talked on the phone, exchanged a few letters, glimpsed each other in passing at my second and third NPL conventions, this was the first time I’d entered Ben’s world, for real, even if just for an afternoon.

We hugged at the door. All very friendly-like we were, but also chaste and quaintly formal. I don’t know if he felt awkward too. I’m not sure I’ve ever been able to tell such things about Ben, for the face he presents to the world isn’t really so different from the stately façade of his house. He ushered me inside and, as if I’d paid admission at the door, led me, straight off, on what felt like an official tour of the place.

He showed me trademarks of the house’s Tudor architecture: tall windows partitioned by narrow lead casings; black, wooden beams jutting starkly from flat white ceilings; roundly arched doorways and heavy doors fitted with black-iron latches and hinges; a huge stone fireplace that must once have been used for cooking—you could still see the dangling hook where a cauldron might hang. Decades later, he still remembers my comment as I followed him from one room to another, the click of my sandals resounding against his barren floors, so that I had to stand still to hear his lecture clearly.

“It’s wonderful,” I said. “Like a monastery.”

I was pretty that day. I wore a knee-length summer dress that twirled whenever I did, which was often. Via Prozac I'd lost my pregnancy weight, and more. How much difference any of this made to Ben, I'll never know, but, along with the giddiness I always felt when given a chance to be a separate self for a day, I found myself in a place of ease. Around Ben, and in Ben's house—so quiet that the ticking of his mantel clock seemed to echo toward eternity—I felt breezy and careless, and began to wonder if I really *had* been nervous to begin with, or if I'd only been playing, once again, a timeworn part in a hackneyed old play. It was thus with everything these days—that uncanny valley between whatever I might really feel, right now, deep down somewhere I could never quite reach, and my everyday chameleon acquiescences to the world around me.

We ate lunch on Ben's screened-in back porch—a sunless, dusty room that seemed sequestered from this house that seemed, already, so sequestered from the outer world. Sandwiches, I think, and glasses of milk, and a shared bowl of strawberries for dessert. We talked about the usual things—puzzles, of course, and the people we both knew who created and solved them. We talked about ourselves too, our family backgrounds, the places we'd lived, our tastes in books and music.

Ben marveled, I remember, at what a “happy person” I seemed to be, and I very nearly gave my usual, dismissive reply to such by-now-familiar remarks: “Oh, that's just the Prozac.”

But instead I nodded cheerily, and answered, “I've been working on that.”

Ben nodded too, and for a moment, then, we were twin bobbleheads, mutually fervent in our faith in hard-earned happiness.

“It takes work,” Ben said, with gusto. “We have to create the life we want for ourselves. We can't just wait for things to happen.”

We pondered that thought, among others, for the next hour or more, lingering over our strawberries on his breezeless porch. Down the block a neighbor mowed his lawn, and when that drone ended we heard the soothing arguments of birds, and the buzz and tap of insects assailing the dark and oblivious window screens. We were especially enthralled with the subject of our mutual happinesses—I suppose now that we, neither of us, had never met another happy person

in our whole lives before. It takes practice, I kept saying, as if I weren't on drugs. He commented that we both seemed to have developed what I would later, brightly call "the habit of joy."

After lunch I perched on his kitchen counter, idly swinging my legs from side to side as Ben put our dishes into the dishwasher. I teased him about the orderliness of his methods—each plate and cup placed parallel to its lookalike; knives, forks and spoons, all pointing upward and consigned to separate sections of the silverware basket. Then we sat in his living room, the upholstery of his tiny couch more comfortable than its stiff-haired look had predicted, and solved a cryptic crossword. And as always, our sitting so close together, the feeling of his arms and thighs aligned with mine, thrilled me to the bone. Perhaps it thrilled him too—but I was starting to doubt that a bit. He tapped my knee with the jovial *esprit de corps* of a teammate, a buddy. A pal, not a lover.

And for the moment this was just what I needed. Solving cryptics with Ben for an afternoon was like playing cards with my brothers and sisters (sans bloodshed). Ben read the clues in his sonorous, avuncular voice, said cheery things like, "Good job!" and "Wow!" when I got an answer right. Meanwhile, synonyms for "affable" kept running through my head: pleasant, friendly, cordial, genial, jovial, nice. Apropos of nothing, I suppose, I asked Ben if he'd ever been a Boy Scout, and he said yes, and recalled those years as among the happiest of his life.

Late that afternoon, as I drove back to Queens, I smiled at remembered gentilities, but found myself sighing most dreamily for the tidiness, the cloistered simplicity of Ben's life. He spent his days entirely alone, fashioning puzzles and games in an upstairs office lined with reference books: atlases, dictionaries, almanacs, anthologies. Books of quotations. An encyclopedia of American movies; a list of every Billboard hit from 1950 onward; books of phrases, fables, legends, myths. The history of baseball. Birds of the world. "The Joy of Yiddish." As I made my winding way again down the Saw Mill Parkway, I measured out the distance between Valhalla and real life, and my heart longed simply for a place upon those shelves—curated, dustless, handled with care, alphabetized by topic.

“I had been hungry all the years”

I suppose I could try to explain myself in those days—my longing, my hollow-heartedness, my eventual infidelities—by reminding you how volatile my marriage was then. But of course, a lot of marriages stumble beneath the stress of raising a disabled child, and as I look back over that time, I see that my husband’s ups and downs, along with my own cyclical reactions of hope and despair, follow more or less the same pattern as Hannah’s. This became especially true once Henry started taking Wellbutrin. From emails to my patient friends and family:

February 8, 1996: *Henry has been doing nicely on his medicine, and apart from his occasional not-enough-sleep crabbiness, he’s been sweet and attentive to me and the kids too.*

February 17: *Yesterday he felt like his old self, all nihilistic and overwhelmed, and it scared him, made him think he was regressing entirely and the whole experiment was a failure... I wish it weren’t so precarious. To have had that week, to see what it’s like to have a real partner, a happy husband, a man who laughs right out loud, who embraces his kids, who’s easy-going... It’s not that everything was perfect, but for once it all seemed to click, it all felt sort of normal—if that makes any sense.*

March 2: *The past week or so Henry’s been laughing easily, telling me he loves me, showing patience with the kids. He’s also been able to cry more easily—at a sappy movie, maybe, or even, a bit, at the heartbreak he’s never been able to face before about Hannah. It’s all new, all tentative, but tonight I took a shower and actually took my time about it, for the first time in ages not listening for trouble downstairs, not ready to leap out at any moment to rescue him from them, or them from him, or each from the other.*

March 23: *Over the weekend a huge fight—or, no, not a fight, because I refuse to fight that way anymore, but a lot of stomping around on his part, a lot of his trying to goad me into saying something hurtful (which worked a couple of times, actually) so that he wouldn’t be the only one in the wrong... It always starts out as anger toward his life—usually Hannah, sometimes his job—that ends up becoming anger at me for not being “more supportive”... So yesterday morning he’s still stomping around, and while I’m talking to a friend on the phone he comes over and pours my tea down the sink and*

throws out the newspaper I'd been reading. We had a sitter coming at eleven, and I didn't really care whether we got the thing resolved by then or not, because I could have a nice time just going out by myself. But then the sitter comes and Henry says to me, "I thought we were going to play tennis," so I look at him quizzically but say sure and go up and change into tennis clothes. And we went to the courts, and we played, all the while with him scowly and me sort of tickled by the absurdity of it all, which I know makes him even madder... He said at one point between serves that he'd made up a "list of grievances," and I said, great, we can pore over it during lunch. But eventually, mid-match, he came to his senses, and by the second set he was apologetic and sheepish, and I never did get to see the list of grievances.

I was, of course, very used to this sort of roller coaster—it was so inherent in the foundation of our marriage that we should have held our wedding at an amusement park. But it seems to me that my Prozac reincarnation brought our problems into a more vivid, high-contrast light. I didn't need him so much now, you see, didn't have to participate in the fights anymore. "Ah, this is argument number 674," I might say to him in the middle of things. "Why don't we skip it this time, and fight about something new?" I simply *couldn't* argue with him—the predictability, the repetitiveness of it all was starting to drive me crazy. But then, just as predictably, my not-fighting would make him angry too, in large part because it frightened him.

"I hated when you walked away," Henry tells me now when I ask him about those days.

"The fighting was awful, but at least it was something—it made me feel alive, at least." I ask him to say more, and, at greater length than ever before, he tells me.

"I was always the last to leave Main Hall," he says, referring to the campus building that housed his office. "People used to joke about it—'burning the midnight oil again'." He'd sit at his desk until well past six most evenings, in those days, filling the margins of his Norton Anthology of Fiction with notes so squiggly, small, and overlapping that he'd have trouble deciphering them when he taught the next day's class. Finally, with no more work to tarry over, he'd trudge homeward, encasing his misery in what he now calls "a suit of armor" that never quite protected him from the onslaught of our family life.

Henry's been reading this memoir as it goes along, and it's shaking him up and stirring his memory--and, to our mutual surprise, this has been mostly a good thing. He seems relieved, at

last, to remember and put words to how things were for him then. He talks about his helpless rage, his longing for escape.

“On the one hand, I was traumatized,” he says. On the other, he adds, “I felt guilty as hell.” The family was sinking, he had been sure of it, and had even begun to think in terms of “triage”: one member of the family must be “sacrificed” in order to save the other three. I nod and remember several desperate times, back then, when Henry had raised the notion that Hannah should be “turned over to the state” or “placed in an institution.”

It was the sort of last-ditch, if nebulous, proposal I heard fairly often during the late nineties, early 2000s. Maybe we should “put her someplace,” various friends and family would—timidly-suggest. To me, the idea remained, in the end, quite literally unthinkable. Moreover, the fact that Henry *could* think of it, I’ve often guessed, may be due mostly to the fact that I couldn’t. He would bounce the “institution” idea hard against the concrete wall that I became, whenever the subject arose, knowing all the while that the ball would never get past me, but merely rebound back to him, plodding and harmless.

“You were a saint,” Henry says, finally, about those days. He admired me, he says, relied on me, felt grateful for the huge “sacrifice” he saw me making. Even so, he shakes his head and sighs. “It’s no fun being married to a saint.”

Meanwhile, by the late nineties, he was losing me, and knew it. Somehow or other, I was no longer merely his “first wife,” and though I must have been flattered to see this change in him—this stunning discovery that he actually *wanted* to be with me--it scared me too, because I could feel in myself, more and more, a longing to be free.

“Your riches taught me poverty”

Ben and I never did have sex, by the way. Oh, a couple of times, both very drunk, we fumbled our way in its general direction, then thought better, and whipped out a cryptic. Meanwhile, I kept visiting him in Valhalla, maybe two or three times a year, and sometimes for days at a time. Once, in the summer of 2000, I stayed with him for an entire month, during which I wrote 20,000 words of a new novel, while he worked tirelessly, quixotically, on the task of falling in love with me.

Or anyway, that’s how he put it. (Sort of.) One day not long before I had to go home, we lay cuddling lazily on his bachelor bed.

“I’ve been trying to fall in love with you,” Ben said.

“How’s it going?” I said.

“I think it’s just not in me.”

“Okay.”

It took me maybe the next five years to get past that particular moment, but I’m pretty okay with it now. Meanwhile, Ben and I have become very, very good at friendship, and especially at cuddling. We have that expertise in common, along with its corollary weakness: an infinite longing to touch and be touched. It was something we learned on an exceptionally drunken night in the mid-nineties. I was lying on his couch with my head on his lap and my legs stretching upward along the wall behind us. He was stroking my hair, and we’d been looking at each other so long that his face had become for me a strange abstraction of shapes and angles. I reached up now and then to feel the stubble on his cheek. I traced the outline of his ears, his neck, his shoulder blades.

And maybe I realized, even then, how rarely things had ever felt this fun, this easy for me—for either of us probably—how seldom we’d been caressed like this, and what a gift it was for us both. I touched Ben, he touched me, and for the moment it was all just fine, and we felt what might have been some small fraction of the impunity that Hannah experienced in her own investigations of the world and its people.

What freedom she must have known throughout her life, never feeling a trace of embarrassment, guilt, or self-consciousness. Hannah traversed the world as if she owned it—or, no, that's not it at all. The very concept of "ownership" would never have entered her mind. Her view was more interesting than that, her feelings more immediate and pure. I think back to all the times she ran up to strangers, in restaurants, in hospital hallways, in classrooms, and cupped their faces in her hands, staring, laughing, sniffing their hair, until—in a welter of apology—I pried her away. I think of how she'd straddle my lap as I sat in the La-Z-Boy, her breath on my neck as she studied the shape and texture of my various freckles and moles, and pulled my collar tautly from my shoulder to examine whatever charming scars might lie beneath.

Hannah knew people both not at all and very deeply. She touched you, she smelled you, she tasted you. She sought to learn what lurked beneath the band-aid on your arm, or how those glinting earrings had attached themselves to your ears, what the veins in your aging hands would feel like when pinched between her fingers, whether those brightly painted fingernails might possibly be detachable.

Meanwhile, Ben and I—we would never come anywhere close to that level of intimacy, and that breadth of curiosity, not with anyone, not even, probably, with our own private selves. None of us can, I suppose—only animals and babies and autistics are so blessed. Still, there was something wonderfully primal in that first sweet night with Ben—a level of physical ease that I've otherwise known only through my children, and only when they were small.

And over the months and years that followed, he became my sweetest friend and my safest shelter. This is true in spite (or, maybe, I'm starting to think, because) of the fact that Ben never fell in love with me, or with anyone else, so far as I know, that he seemed and seems incapable of that depth of feeling. He remains gracious and warm, but he's not "deep." I thought he was, in 1995. I thought he was repressing huge emotions that needed only a bit of prodding and a lot of wine to bring to the surface. But he's persisted, over the years that followed, in attempts to dissuade me of that notion. He is what he is, he says—no less, but also no more. And at times I've come perilously close to believing him.

And this may be the best part of our friendship—that he's the one person in the world I still can't

“read,” and, more to the point, the one person from whom I can *never* sense pain. With everybody else I’m *Star Trek*’s Counselor Troi, you know—the professional empath who shares in everyone’s darkest fears and longings. For all my life it’s been my superpower: automatic, inexhaustible empathy. (That, and parallel parking.) But around Ben that power can afford to switch off, and the wailing world goes quiet. Over the years, Ben became more truly than ever my heart’s shelter from a hard world, and he’s been that for me ever since—even these days, when life is very different for me, and I don’t seem to need so much sheltering as I did way back then.

Once I wrote a poem for Ben:

Mendicant

*Your house is the plainest of churches. Yet
how like a nun I find home there. I tiptoe so
the wood absorbs my step, so that your ceiling,
heaven-high, won’t broadcast echoes*

*of my graceless gait. Rough wooden beams
arrogate all dreaming here. Logs huddle
tight against the empty hearth. Likewise,
the daylight, muffled and oblique, worms*

*furtively through windows fortified
by stalwart iron traceries. Your halls:
made slim by dusty breveries stacked flush
along their borders. Narrow, too: your bed.*

*And yet what cosseted relief I find inside
this counterworld submerged in sepia. An old
clock strikes its hollow hour, somewhere,
in a distant room I seek to leave unfound.*

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“The soul selects her own society”

Hannah’s schooling got smoothed out (or smoothed over?) eventually. By the fall of 1997, she was back full-time in a special ed classroom. She had a new aide, Danene--a patient, energetic woman of about 35, I guess, who worked wonderfully with her. The thing I liked best about Danene—among many virtues—was her playfulness. It’s something I’ve noticed, through the years: For Hannah’s best teachers and aides, the trick was not minding. That is, the smoothest way through hard times lay in not taking anything too seriously. For a while, especially on Prozac, I was like this myself. After all, life with Hannah could be goofily delightful sometimes.

She had a lifelong love of nakedness, which tended, especially as she got older, to cause the occasional social scandal. In her younger days, whenever Hannah went outside to play, I tried to dress her in what I hoped were unremovable outfits: overalls, mostly, with a shoelace hitching the straps together tightly at the back. Still, she found ways to free herself—she was an ecdysiast Houdini, in fact—and often I’d discover the trail of her shoes, socks, overalls, shirt, and diaper before I discovered the girl herself, naked and ecstatic and swinging as if to tap the sky on the back-yard swing set. Then as she got older, as we groped through the era of toilet training, she needed to wear removable clothes, so I ended up just taking my chances: dressing her normally, and then checking on her now and then to make sure she was still dressed.

Not that I minded her being naked around the house. Sometimes she’d be jumping high on the full-sized trampoline we’d installed in her bedroom, whose big bay windows fronted on our busy street corner. I hoped, and eventually came to assume, that people driving up Excelsior Street toward Walkerville would simply get used to the little naked girl bouncing up and down, up and down, on the top floor of the white house on the northeast corner of Quartz Street. The set-up got worrisome only when Hannah entered puberty, which happened earlier than any of us would have preferred. She had her first period when she was eight. It’s a common thing in autistic girls—“precocious puberty,” they call it. Hannah’s medications, moreover, coerced her young body into gaining more and more weight, so that, by the age of ten, she’d developed a rather womanly figure.

We couldn’t close her bedroom curtains because there were none—she pulled down every set we put up. And really that was just as well, because, for Hannah, looking out at the oscillating view

was, I think, a big part of the thrill of trampolining. Eventually, as became my tendency with a lot of things, I decided not to think very hard about what people thought of us. I'd check on Hannah periodically, and put her clothes back on her whenever it seemed my duty—the process of which she was always quite tolerant, even as she clearly saw no point to it whatsoever. In time, of course, she could dress and re-dress herself, so long as we were persistent in coaxing her, and didn't care if she got it 'right.'

By then we'd installed a massive, sturdy wooden playset in the back yard, and when the weather was even the slightest bit warm, Hannah spent a lot of time back there. She would hoist herself onto the highest redwood crossbeam—her sense of balance had always been preternaturally steady—and would scamper back and forth along it like a tightrope runner, sometimes clothed and sometimes not. From that heady height, drivers could easily see her: to them she hovered like a dream above the tall hedges surrounding our back yard. And now and then some well-intentioned citizen would call the police about the young naked woman who stood, bouncing and shouting and flailing her arms, on full, busty display at the corner of Quartz and Excelsior.

Thus, I would glance out the living room window one day to find a policeman heading up the sidewalk to my front door. (The first alert elicited *three* police cars, in fact—buxom public nudity being the sort of crime that demands the law's fullest attention.) I'd apologize and explain, and run out back to get Hannah dressed again. They, the police, were always very nice about the situation, and eventually they stopped showing up at all, but merely sent us an occasional friendly honk as they passed our pandemonious house in pursuit of more noteworthy business.

Our friends were understanding, too. Once, during our annual Hanukkah party, Hannah came roaring down the stairs, rosily, bouncily naked. And as she made a beeline for the buffet table, plowing through the benignly gaping crowd and jabbering at full volume, we passed the whole thing off as a little-known Hanukkah tradition.

It was among our best small-town advantages: that eventually just about everybody in Butte came to know Hannah, at least in passing. I was forever taking her places and watching as people—kids, adults—came up to say hi to her, as they called her by name, leaned in a bit, and tried to catch her eye. She seldom replied, in any form, to any of them, of course, but it soothed

me to see that Hannah was part of the community, and that people not only knew her but liked her—or at least, I don’t know, liked the *idea* of her somehow. They took, I think, a quiet little pride in having had contact with her, embraced the warm feeling they got when they were nice to her, even if, naturally, they never really “knew” Hannah at all.

The uncommonly communal spirit of Butte, Montana—that deep sense of all of us scrabbling up the same steep hill—came in especially handy the first time Hannah disappeared from the house. It was a warmish fall weekend day when she was eight years old. Henry was out of town, at an academic conference in Seattle. I’d accidentally left the front door unlocked, and I don’t know how long it took me—five minutes?—to realize she was nowhere in the house or yard. I brought Becky, still a toddler, and walked up and down our streets a ways, thinking Hannah wouldn’t have gone far. When another ten minutes went by and she was still missing, I called the police to help me look, but they couldn’t find her either.

And then, gradually but soon, all manner of other people showed up at the scene. Who knew that listening in on the local police scanner was such a popular avocation? But here they all were, within fifteen minutes of the alert: two or three dozen volunteers, combing the neighborhood. A few of them knew Hannah pretty well—three of her teachers showed up, along with other people who worked at her school, plus a couple of case workers from Family Outreach. But a lot of the searchers were strangers. I remember kids on bikes, neighbors I’d never met before, a couple of Henry’s students, a guy on a motorcycle who cruised up and down alleyways, peeking into back yards.

In the end—after another hour of looking—it was I myself who found Hannah. It turned out to be very simple. Becky and I walked only a couple of houses further down our sidewalk than we had on our first investigation, and saw a front door wide open, and I thought, well, yeah, of course.

“A clue!” I said to Becky, who at the age of three already shared my love of puzzles. “Aha!” she said, with the hushed intensity she usually reserved for Easter egg hunts, hide and seek, and our new favorite TV show, *Blue’s Clues*.

We knocked and called at the open door; the owners weren't home. We ventured inside and peered around. The main thing I remember, the thing I seemed to see most quickly: the kitchen's refrigerator, its door wide open.

"Another clue!" I said to Becky.

"We need our handy dandy notebook!" she answered.

We sneaked our way upstairs and found Hannah in a child's bedroom, sitting on the upper mattress of a metal-framed bunk bed. Unfazed, cheerful, letting out the occasional, exuberant "Bah-dah-BEEEEEE," she sat gazing out the bedroom window, pulling at the side of her eye to set straight the slanting sunlight. She was trapped there, at least nominally: her bare foot wedged between the bedframe and the top rung of the ladder. It took only a minute to free her, then to lead her out, back up the sidewalk, home.

A couple of things make this story more memorable to me than it would have been anyway. The first is that, throughout it all, I didn't panic (thus neither did Becky). Rather, I just assumed my perennial assumption: that Hannah would be fine. For, as I've said, I always believed, at the bottom of everything, that Hannah was bulletproof—as if the simple, loud fact of her autism rendered her immune to any further harm. I remember at a certain point, maybe five minutes before I found her in the neighbor's house, I felt I should *pretend* to panic, at least a little, because the people around me seemed not just to expect but to desire it. If only because then they'd have something clearcut and satisfying to do, they seemed eager to console me, and I wanted very much to accommodate them.

But even more striking than my lack of panic was the feeling of pure, helpless love I felt as I looked around at all these eager, gentle people trying to find my daughter. Honestly, I felt like I should throw them all a picnic afterwards, order pizzas, haul out lawn chairs. The crowd let out a collective whoop as Becky and I led Hannah, clad only in her big-girl diaper, out from that house down the street, and then, as a round of hand-clapping and hugs dwindled into a buzz of happy murmuring, people just kept standing there, grinning, nodding, reluctant to disperse, and meanwhile I felt painfully averse to seeing them go. For the hour of the search, I'd felt part of something larger than just our cut-off, bedraggled little family. For now I felt part of a cut-off,

bedraggled little community. I'd learned something fine about Butte: that people here were willing to go out of their way for Hannah, that even those who didn't know her at all somehow cared about her. I got the feeling—not right then but when I thought about it later—that as Hannah got older, and even after Henry and I were dead, Butte would always treat Hannah kindly, in whatever wise or clumsy ways it knew how.

“The incidents of Love”

A few more little stories, which I tell you, mainly, in order to hold onto them myself:

There lived in Butte a fine young man named Jim Kelly. Jim had renovated the gym/auditorium of an abandoned elementary school up the road from us, and turned it into a padded wonderland where he taught gymnastics to children. Henry and I brought Becky and Hannah to one of his classes one day, just to see if either daughter might be willing or able to take part. The trip was pretty much a bust on that count. Becky, maybe five at the time, was too shy to leave my side, let alone allow herself to be guided, like the other kids, into forward rolls or along balance beams. And Hannah was Hannah, unable to cooperate at all with the lessons, but reveling in the wide-open space of the gym, and in the padded floors, the parallel bars, the pommel horse. She was drawn most magnetically to two huge trampolines Jim had set up at one end of the room, on the elevated stage of the former auditorium. I talked with Jim for a few minutes, and without much in the way of my having to explain things, he said that as long as his students weren't using the trampolines, it was fine for Hannah to jump on them herself.

Very soon Henry and I were bringing both kids to the gym every day Jim held classes, and the place became for us a reliable utopia. Hannah headed straight for the trampolines and would quickly get lost in her own bouncy ecstasy, while Becky hung back to observe the circusy atmosphere. Meanwhile, Jim Kelly in his trim gray sweats, and his somersaulting gymnasts in their tiny pastel leotards, would hear Hannah's whoops and yelps, and might glance her crazy way now and then. But when we worried that our presence disrupted their lessons, Jim was quick to assure us this wasn't so. Hannah was always welcome, he told Henry and me, and in fact—though he hardly knew us at all—by the end of the third week of our acquaintance he'd made an extra key for the gym's outer door, and gave it to us so our family could go there whenever we wanted, even when Jim wasn't around. Of course we offered, and kept on offering over the next several months, to pay him something, even just a token amount, for this astounding generosity, but Jim refused, forever, to hear of it. And all this went on for about two years, for as long as Jim's little business survived.

And there were so many others who went miles out of their way to help my daughter. I suddenly picture myself, lying flat on my back in our local dentist's chair, with Hannah lying upright on

top of me and my legs and arms wrapped around her writhing body. Meanwhile, one hygienist holds her arms in place while another tries to pry her jaw open. The dentist's brother, who had just happened to be stopping by the office, lays his body across both of us, and then Dr. Bartoletti, forever imperturbable, leans in close, surprisingly agile in his efforts to keep Hannah from chomping down hard on the handle of his dental mirror.

Or Hannah at the starting line of a Special Olympics race: When the gun goes off and the other girls start running down the track, Hannah stays just where she is, paying no heed at all to the dozens of onlookers—parents, teachers, volunteers—now urging her to take at least a tiny step forward. Even once the other runners have finished the fifty-meter race, Hannah's handlers won't give up on her, and finally one of them—I think it's her aide, Danene—runs to the finish line and holds up a cookie. Hannah saunters toward the cookie and in the process crosses the line, to a round of cheers from friends and strangers alike, and a fancy white ribbon for fifth place.

A few years later, Hannah's in high school, and the special ed teacher there calls to ask if I can bring her a change of clothing—she's had “a major toileting accident.” I come in with the clothes, and take Hannah to the women's locker room. I get both her and myself undressed (it's easier that way), then stand with her under the shower, rinsing off the collective mess. She's not cooperative—lots of whining complaint and the occasional attempt to head-bang—but she's manageable. And then, beyond our line of sight, I hear two teenaged girls enter the locker room. One, it seems, is a transfer student, and the other girl's giving her a first-day tour. They hear Hannah's commotion echoing loud from the shower area, and after a moment I hear the guide say to the new girl, “Oh, well, I guess now's as good a time as any to tell you about Hannah. She's great. But she takes a little getting used to.” Perhaps it's just the way words echo in that cavernous room, but I hear affection, an almost familial pride, in that girl's round voice. And it seems to me then, as Hannah and I cling wetly together, curtained by steam, that this is the way Hannah's life will always work, as nearly everybody in her daily periphery starts out nervous and then gets used to her, inducts her into their everyday view.

One year the city wanted to modernize Hannah's favorite neighborhood park. They laid down truckloads of sawdust and placed a big, sturdy plastic play-gym on top, and then they took out

the old rubber-seated swing that for at least a generation had been dangling there from long chains descending from a stolid, gunmetal arch. It was only common sense to remove that old swing, with its chains that pinched young fingers, its black rubber seat that burned young legs all summer. But then a friend of ours, who lived across the street from the park, realized that now Hannah had no nearby place to swing. Without mentioning it to us, she wrote up a petition, gathered signatures from other neighbors, and took her case to the city planners, who graciously (and crazily) agreed to reinstall the old swing. Thus, in fact, if you should happen to drive by that little park even these days, you'll still see that tall arch. Its ancient gray shadow serves, for the neon-cheerful plastic toys nearby, as a sort of *memento mori*. But sometimes, driving by today, I'll still see a kid there, swinging or swaying or spinning in circles. Other times, the swing is empty but, breeze-driven, moves on its own.

“The heart asks pleasure first”

Peter was a carpenter. He was married to Abby, one of Henry’s finest and favorite students, and I met him for the first time when the four of us went to dinner together, on a summer evening in the late nineties. Abby and Henry were friends, and at first I’d simply assumed she was in love with him. After all, so many of his students were in love with Henry, for the usual excellent reasons: he’s handsome and brilliant; a good listener; funny; a feminist. True fact: once, in that era, we were leaving a bar when a sweetly drunk young woman dashed over to me, grabbed my hand and shook it. “I just wanted to meet the woman who married the perfect man,” she said.

(“So would I,” I might possibly have thought to myself then, though more likely I made it up later.)

But Abby—a perky, funny, pretty woman in her mid-twenties—was Henry’s friend, and no more. She’d told him a lot about Peter: that he was a brooding man, consumed with longing, regret, and implacable anger in response to the lousy way his life was turning out. (Needless to say, Henry wasn’t looking forward to this dinner.) And it’s true that at first, that night, Peter was stubbornly quiet—taciturn, even. As if in retort to an unspoken dare, he heaped his tortilla chips with the hottest of habanero sauces. He folded and re-folded his paper napkin until it was a thick, impervious square. He glared at his margarita, as if to decide, once and for all, which of them would blink first.

But in those days, I don’t mind admitting, I was fluent in magic, and by the time our fajitas arrived, my pharmaceutically enhanced charms had coaxed Peter into a state of guarded geniality. It turned out he was a Butte boy, born and raised, so I got him talking about Butte, and eventually hit on a sub-topic that roused him into life: Butte’s most famous native son, Evel Knievel.

“He’s a thug,” said Peter happily. “He ought to be in jail.”

I rubbed my hands together. The trashing of Evel Knievel is a longtime Butte tradition, and I’ve always found it fascinating. “Examples, please,” I said, and Peter was off to the races.

After dinner, the four of us went for a walk along the sidewalks of uptown Butte. Peter and I strode ahead, side by side—we were both such vigorous walkers—and quickly I had him talking

and laughing and even “opening up” a bit to me. This, after all, was my specialty in those days: I was a sort of Anne Sullivan for depressed people. I did it all the time at puzzler conventions—picked out the shyest person in the room and then, as if I’d made a bet with myself, walk up and perform my flittery little conversational dance for them, and they’d be won over, every time (nearly), and, so far as I could ever tell, they’d walk away from the encounter with the feeling that I found them pricelessly delightful.

Which I both did and didn’t, if that makes any sense. In part, I confess, my flirting was merely a dumb little game I played to test the scope of my newfound irresistibility. And soon, in fact, it became a bit of a problem at NPL conventions, as I’d walk into a hospitality suite or a ballroom, and a dozen people—most, but not all, of them men (I also had a way with old ladies and toddlers)—would light up with the thought that I was there to see them and them alone. Or, anyway, I *assumed* they lit up for me. For all I know, it was just another trick of the chandelier’s flicker.

I look back at those times now, trying to gauge the exact degree of my narcissism. I remember once sitting with puzzlers at a crowded breakfast table and purring like Scarlett O’Hara, “I declare, I suddenly feel a rapacious thirst...” just to see how many of my fellow diners would leap from their chairs to get me a glass of water. But that’s as close as I ever got to becoming a true *femme fatale*. Nowadays at conventions, when my attentions surely don’t matter so much anymore, I still give each friend, by now as familiar as family, as much attention as I can, complete with flinchless eye contact and a pretty good memory for their jobs, relatives, tragedies, dreams, obsessions, etc. And they mostly remember mine, and we get along well, like a flock of geese home from migration.

With Peter there was something else, which we both felt from the get-go. Our attraction took the form of an immediate, primal desire I’ve rarely felt toward any man, before or since. I tend to be drawn to a smart man’s mind—and, somehow viscerally, to the various fetishes of intellect: eyeglasses, graying temples. A *de rigueur* beard, closely trimmed or abandoned to anarchy. A halting, measured tone of voice. Wrap him up in a tweed jacket--rumpled, frayed at the collar and cuffs--and I’m agog with glee. Yet the first things I noticed about Peter were the taut veins and muscles of his forearms, and for an improbably long time that was all I needed to know.

Peter and I spent many hours together that summer and fall, letting our flirtation play out to a tantalizing degree. I don't know that either of us ever "fell in love" with the other, but even so it was a dizzying adventure—and not merely because, in its tempestuous process, I learned a hell of a lot about carpentry. For carpentry was Peter's staunchest commitment, by far—the vocational choice he'd made after four disenchanting years working in St. Louis, Missouri, as an aerospace engineer for McDonnell Douglas. Leaping from that golden ladder, returning to Butte, learning instead to work with his hands on projects he could own, and touch, and take pride in—all this had served as his fierce attempt to waken from what he'd found to be a soul-numbing capitalist dream.

Within a few weeks of meeting him, and no doubt inevitably, I had Peter building things for me. His first project was the sturdy, redwood swing-set/slide/jungle-gym/sandbox hybrid that for the next several years would dominate our small back yard. Swinging was one of Hannah's *raisons d'être*, of course, but she was getting so big these days—taller but also heavier—and she was such an avid, wild swinger that we needed a playset as durable as the airplanes Peter had once helped design. That job done—and a grand success—I commissioned Peter to renovate Hannah's bedroom into what I hoped would be her sort of sanctuary. In what had once been her walk-in closet, Peter installed a ball pit—the kind they used to have at McDonald's before rumors spread of what lurked beneath the plastic balls (diapers, hypodermic needles, rattlesnakes, etc.). I ordered thick gymnastic pads to line the walls of her room, and had Peter build bunkbeds too, so Hannah could climb. He added a hammock so she could sway and cocoon herself, and even—the room was just big enough—a full-sized trampoline, bolted to the floor. Peter also plastered over head-cratered walls all over the house, and repainted our living room. These projects took weeks to complete, and in the meantime Peter got to know my young daughters very well, and felt easy around them both. Becky liked to steal his baseball cap and make him go look for it. Hannah liked to climb him like a tree.

We developed a ritual of going out on Monday nights to play pool and watch football at a local bar. Sometimes Henry and/or Abby would come along, but usually Peter and I went alone. Abby, of course, knew all about the attraction between us; the three of us talked together about it often, in fact, toward the fizzling end of it all. But Henry never seemed to know a thing. I even remember bringing it up one day with him, asking if he ever worried about my friendship with

Peter, and he said he didn't. He knew me to be "a person of absolute integrity," he said, which made me wonder if he knew me at all.

Still, he could see that something was changing. From a letter I wrote in the winter of '97:

Henry told me yesterday that he doesn't worry about some other man getting me. What he worries about is that nobody will get me, including him. All this independence of mine—really, I'm not sure you know how clingy I used to be with him, but the change has been dramatic, and it's shaken him. Still, I told him, and it's true, that I love him very much, and that things can be so much better now between us, because I'm choosing to be with him instead of feeling forced to by neurotic need. I really do love him, more than ever, and there's no one else in the world I'd rather share my life with. So what the hell's going on with me? Why do I keep hovering on the verge of messing it all up?

We'd been together for fifteen years at this point, so maybe Henry knew me pretty well. Or, anyway, he knew me about as well as I knew myself in those days—which may not be saying very much.

“I heard a fly buzz when I died”

From an email to a friend, March 25, 1996:

First chance in a long while just to sit here uninterrupted. It's been a hellish last few days—or, really, mainly the nights have been hellish, the days just a long dreary process of trying to recover from the nights. Hannah's been so awful, worse than I can ever remember her being. She's going through some sort of internal agony, and her rages go on all day with only an occasional subsidence, and now they've started to go on and on through the night as well. Two, three in the morning she'll suddenly wake up screaming, start banging her head horrendously hard against the closest hardest surface. (She broke a window yesterday.)

I go in and lie with her, hold her down as she strains to bang her head some more, try to keep her from pinching me, clawing me, biting me, ramming her head backward against mine. Hours go by this way, me holding her down and her trying desperately to get free enough to hurt herself, with here and there some little time when she seems to be settling down, maybe drifting back to sleep, but then suddenly starts up all over again, so that real sleep doesn't come till early morning, by which time I've gone through so many phases—all manner of maternal strength and perseverance, of course, and then a numb, mechanical efficiency, and then the imagining how it would be just to kill her, whether that would be the best thing for everybody and then how it ought to be done, a straightforward smothering with a pillow or something more thought out, more clearly like an accident: throwing her out the window and saying she plunged through on her own, and wondering how it would all transpire, the sirens and the neighbors and my own hysteria, and wondering whether the police would believe me, and what they'd ask and what sort of situational witnesses would come forward, one point of view or the other, and then the one thing I can never actually bring myself to consider with any clarity: how calm our lives would be, forever after. By six a.m. I've sobbed the whole thing through, for the moment, and I'm just tired, tired. I'm still holding her down, or maybe she's finally asleep and I've crawled back into my own bed, and then it's Becky's turn to wake, and another day begins.

“Wild nights! Wild nights!”

My affair with Peter--and, yes, that's what it officially became, I guess, according to the laws of God and man--never amounted to much. The clumsiest part was the consummation, rivalled only by the night Abby and Peter and I fumbled through a silly *ménage à trois* in the dark. As perhaps any idiot could have predicted, the best parts had already happened: those breathless moments of frisson before we finally made it “real.”

How furtive and reckless we had been, by turns. We held hands openly, in dark but public places. I remember a night at the bar where we watched Monday Night Football. The waitress there happened to be a former, much loved babysitter of ours named Kim. It was lovely to see her again, and of course she treated us warmly. But as the evening went on, and Peter and I leaned in close together, his hand over mine, he gradually pulled back with an abashed grin, then whispered, “She’s spritzing me, you know.” And it was true. For the past several minutes Kim had been wiping down tables behind us, and whenever she got close enough, she’d turn her spray bottle a trifle askew, delivering a mist of cold water that drizzled down the back of Peter’s neck.

I liked to trace the veins on his forearms. I loved to watch him play pool. It drove him crazy just to see me walking barefoot through a grassy park. He also loved the shape of my thumbs. (I pause for a moment to look at them now...and, yes, I can see his point.) We held each other very tightly many times, on a dance floor, maybe, or on his couch when Abby wasn’t home, or in an endless series of lingering goodbyes. Once in the middle of a lovely day we were cuddling on the swing on my screened-in front porch, and suddenly Peter pulled me down to the floor and covered my mouth, because the mailman was approaching, and the mailman was a friend of his, and he didn’t want the mailman to see us there like that. Silly but true: even as I write about it today, I can still feel the thrill of that small moment.

I wrote to my sister, in the spring of ‘97:

Peter’s much more overtly sexual than Ben would ever dare to be. The other night playing pool I missed a shot and said something like, “I can’t help it—I’m always so giddy in your presence.” It’s the sort of flirty remark I’ve made to Ben a dozen times, and Ben never does much but smile, but Peter looked at me intently and said, “And why is that?” And it was like he knew exactly what I was saying and wanted me to know he knew

and wanted it out there. Today at lunch he and I were talking about personal things again, and about fidelity and social mores and all, and I said, “But the thing is, I do believe in monogamy, or at least I know that if I suddenly said I didn’t, it would be incredibly convenient all of a sudden.” ...This thing with Peter—it’s a sort of refreshing antidote to Ben, especially after talking with him (Ben) on the phone today, after not having talked in a couple of weeks: I told him, “I miss you...doesn’t that seem strange to you? I mean, not that I feel it, but that I should say it right out loud the way I do?” And he wouldn’t rise to it, wouldn’t say he missed me too... Maybe he doesn’t miss me. I really can’t say, though during the rare times he’s right there beside me and our eyes are meeting, I feel sure he feels something for me. But instead he answered, “No, it’s not strange at all. I like it. You’ve a very warm person, and I like that about you.” And I suppose that was the moment when I thought, well, fuck it then. With Peter the sex is right out there on the surface, which I find so much more delightful right now.

And then there’s this, written a few weeks later, after Peter and I had been out dancing to a local band:

As a sort of experiment, I looked around the room and my eyes finally settled on the drummer of the band, who is a friend of ours (helped us move), whom we’ve had over to dinner a few times, and I thought, “Well, do I want HIM too?” and as I watched him drumming I thought, yes, I could definitely see wanting him. Then I looked at the lead guitarist, whom I’ve never even spoken to before, and I thought, “Yes, and him too.” It wouldn’t have to be Peter at all, I decided. It’s the thing itself I want—whatever that is, really, however that would be played out. I’m standing on a cliff, daring myself every minute just a little closer to the edge.

It wasn’t until the following summer—1997—that I dove headlong off that cliff, and even then (and somehow it embarrasses me to say this) I had permission to jump. Henry and I had managed to take a trip to the Bahamas that January, just the two of us, and in the course of a lovely week there I’d brought up the idea of having an “open marriage.” I hadn’t told him the details of last year’s dalliance with Peter, but he knew the gist, and since he couldn’t imagine what I could possibly see, long-term, in such a brooding, obdurate man (“frying pan to the fire,”

I think, was the shorthand we used), he never saw Peter as a threat. That day in the Bahamas, I said (and probably even believed, for such was the way my mind worked then), that perhaps we were secure enough these days. Perhaps we could have sex with other people now and then, and it wouldn't damage us as long as we set up the right rules. Henry was straightway intrigued, to the point where I realized he'd been harboring the same idea—and, in a state of cool dispassion, we set about to work out the rules. We were like doctors, professors, legislators: the sorts of people who, against all odds, had never learned to recognize the vast difference between theory and practice. Thus, it was decreed, on a clouded-over day on a pristine beach on Emerald Bay—the trinity of rules that would surely make the thing run smoothly: No pregnancies. No diseases. No broken hearts.

It was harder for him than for me. I had most of my affairs at puzzlers' events. They were one-night stands or afternoon interludes. They were sweet and friendly encounters, and we all knew the rules, and we got along just fine. Well, pretty much, anyway. There were a few men, along the way, who fell in love with me, or thought they did, for a while. The convention would then be followed by a flurry of ardent emails and awkward phone conversations, and on two or three (blessedly separate) occasions, men flew out to visit me for a week at a time, which was a bit awkward with Henry right there, but what could he say, rules were rules. And—softly but inevitably—I'd always end up letting these sweet men down. The fact was that I had very little experience with *having* suitors, let alone keeping them at bay, and it tended to surprise me if ever they ended up hurt, and especially if they felt “led on.”

I became a character in a Joni Mitchell song—all flowing gowns and beveled mirrors, and larks building nests in my golden hair. “She will love them when she sees them, they will lose her if they follow...” That was me, for two or three years, and most of the time it was simple and harmless, but occasionally I hurt people, and to this day I'm sorry about that, though I have no illusions that any of them pined for me for very long. Those years were, for me, all just one long sociological experiment—for a while I used to joke that I was the Margaret Mead of fucking—and it included threesomes, orgies, the trying on of various fetishes and games. It was all the sort of thing I probably ought to have been trying out in my twenties—and, to some extent, I had. Still, here I was, pushing forty, and again I was up for anything, and wasted little time in finding it.

You must understand that I don't regret a moment of it, not even those moments most deeply regrettable: the time I had sex with one man just to kill time until the next man was set to arrive. The drunken ménage with two NPL convention drop-ins--"the Mensa boys" is how I label them, because they were always trying to insert the fact of their membership into their pickup lines, and also because I can never remember their names. The "sex party" where after twenty minutes, and three, somewhat perfunctory orgasms, I felt so bored I was grateful that at least the food was *amazing*. The various sweet, patient women I tried so hard and long to please, even as, despite having a similar anatomy, I had absolutely no idea what I was doing. There were many fine, fun, and ecstatic moments as well—but those stories, well told, would serve purely as fabulous but gratuitous pornography, so I'll save them for the movie version. Overall, the process of "reclaiming my inner slut" (or however a strong young feminist would label such a corrective) was a good, and fascinating, thing to have done—if also, in the end, a good, and insipid, thing to be done with.

Henry had two affairs of his own, with smart, local women whom I knew and liked, but to his surprise each relationship in its turn became complicated, tangled, with love and eventual heartbreak on all sides but mine. I watched each of Henry's affairs from far away, it seemed, watched it as it rose and rose then finally hurtled to earth again, and I tried to be supportive of Henry, and of the women too, since they were both my friends and would sometimes seek my advice. What they couldn't see was that I myself was separate from their drama, caught in another place entirely—and where was that? Nowhere, really. I was loving, but somehow empty of feeling—my heart was "full and hollow, like a cactus tree," as Joni Mitchell wrote. Meanwhile, our daily lives of stress and exhaustion, the occasional hope and the ultimate feeling of failure, went on as they always had. And even at the time it occurred to me—it seemed obvious, Psych 101--that I was using sex, and Henry was using love, which he really seemed to feel for each of these women in turn, as an escape from the harshness of our everyday lives.

“The brain is wider than the sky”

“If I could snap my fingers and be nonautistic, I would not. Autism is part of what I am.”

—Temple Grandin

I went to a conference in Seattle once. The keynote speaker was Temple Grandin. Dr. Grandin (but how silly to call her that when to me and to all the autistic world she’s simply “Temple,” as if she belonged to us, and we to her) is a professor of animal science at Colorado State University, and has devoted much of her career to the rights of animals, in particular the development of more humane ways to treat livestock. She’s also, and not incidentally, autistic, and her accounts of what her autism feels like, and the ways she’s found to palliate and harness it, are, without question, the most insightful and articulate teachings I’ve ever come across.

Temple is magic, somehow. To her nervous, neurotypical audiences she’s an icon, a sort of patron saint. In our hope-ridden despair, we take comfort as she guides us beyond the big enigma. She can’t solve the riddle for us but she takes us to its looking-glass other side, where—how could we not have known?—she lives abundantly. As Temple Grandin limns the path of her life and thought, we can’t help but notice, commingled with her struggles, an abiding spark of joy. In this way, she seems to mirror our children’s souls back to us—and, oh, how they shine. As I write this, a phrase leaps into mind without my willing it: ‘triumph over tragedy.’ It’s the angle usually taken by the magazine and TV reporters who interview Temple Grandin. It’s also a catchphrase for the American dream, and right now it sends a shiver of dissonance down my back, then leaves me here, struggling for hours for ways to translate that shiver into everyday prose. In the end I give it up, and write this clumsy poem instead:

Thinking about Temple Grandin

*To triumph over tragedy. How odd
to think of either word without a clang
of chaos in your head. As if some god
decides what sub-division you belong*

*to, up or down. As if there's up or down
at all. Your tragedy remains. Or else
it never was. Or else to swim/to drown
are synonyms, as each word melts*

*the other. We can't know what's tragic. Nor
can we discern—not yet—what triumph is.
Yet both words thread their silver through your hair.
Their twin ghosts glisten through your cowgirl eyes.*

Temple Grandin's autism is, of course, integral to her. Like most things, once you really think about them, it's both asset and burden at once. At the conference in Seattle, she began her speech by noting that her negotiations with the neurotypical world were still a work-in-progress. She was always learning and practicing new social skills, she said. Eye contact, for instance—she was working hard on that these days. And from my vantage point in the first-row center seat of the big auditorium I could see the tenacity of her resolve. For—this is really true—throughout her entire talk, except for an occasional sidelong glance at images projected on a screen to her left, Temple never took her eyes from mine. Nor, for that matter, did I look away from her, but only nodded, blinked now and then, and smiled with such vigor that I became quickly a caricature of attentiveness. By the end of her speech I was grinning like the village idiot, but no matter. Our bond that day—however fleeting and (let's face it) accidental it was—has endeared her to me forever.

After the speech (which was delightful, as Dr. Grandin herself is—all the more so for not seeming to know she's delightful at all), a mob of us engulfed her in the hallway, so she signed books and tried to answer a few questions. It was a poignant scene. So many of our questions were heartbreakingly specific: 'My son's on 25 mg of Ritalin every day, on a strict gluten-free diet, and we're doing forty hours a week of ABA with him and we've also been trying some holding therapy—can you recommend something else we might try?' And tireless, patient Temple kept having to say that these were the sorts of questions parents should bring up with their own doctors, that no one had the expertise to assess an autistic child's therapies without ever having seen the child before. Yet many in the crowd persisted with elaborately personal questions, while

others—this was the category I fit into—seemed pleased enough just to stand there, as close to Temple Grandin as decorum allowed, and to bask in the grace of her hard-won wisdom, to touch (at least figuratively) the hem of her garment.

So there we were. And there, surely, a lot of us remain: a beggarly horde of parents, clamoring for miracle. We learn the latest theories, practice the latest ‘interventions.’ We spike our speculations with anecdotal magic. We measure out our children’s lives in teaspoonfuls of vitamin B6. We grab for gurus, experts, breakthroughs, momentum. We seek, if nothing else, some tiny glimpse of explanation for the labyrinthine detours our family’s lives must follow. “The worst thing you can do is nothing,” Dr. Grandin lets us know. And so we try and try.

“I cannot live with you”

December 31, 1998. It was early enough in the evening for the ER not to be crowded yet, but we still had time to kill while we waited for our turn with the doctor. So Henry and I wrote a sonnet together—I wrote the odd-numbered lines, he wrote the even ones. We called it “New Year’s Eve at the Emergency Room”:

*Emergency! There’s something up her nose!
She’s on the metal cot, asleep for now.
While, we, bored parents, sit, and stare, and doze.
At least we’re not about to have a row.
No, Nancy’s scheming: “Shall I steal some gauze?”
– While Henry’s drawing pictures of his shoe.
Despite the wait, we’re managing, because
There’s nothing fucking else for us to do.
The doctor comes, then goes. Will he come back?
–Thank God, he’s here! Indeed, it seems he’ll stay.
We gird our loins, preparing to attack
Whatever’s up our daughter’s nostril. Hey—
It’s out! (It was a cap of some sort.) Thus,
This year won’t end too hellishly for us.*

We got along well, Henry and I, except for all the times we didn’t. We tried, even in the worst of times, to be stalwart friends, even as we remained terrible at the sort of balanced partnership that a marriage—especially a marriage under great stress—requires. Partly it felt as simple as this, from a diary entry in 1996:

Really, Henry wasn’t meant for the sort of life he has. He tries and tries to adapt, and he’s partly getting better at it, incrementally over time, but it’s all so hard and none of it comes easily or lasts without lapses.

But it was also more complicated, for we were both far too bound up in our disparate roles. Henry played the inept, impatient complainer, always on the verge of falling apart. Meanwhile, I played the blameless, self-sacrificing saint. To Henry, I always seemed to have virtue on my side, for he had always—every day of his life, even before we had Hannah, even before we met—felt himself to be a selfish, blameworthy man, which in turn made him defensive and angry. I, for my part, have never been comfortable feeling anything but virtuous. I’ve always had to be the good one, all my life. And, especially in my relationship with Henry, I always needed to be right. Often it was my only consolation for feeling so unloved. Thus, the two of us worked stupidly hard to ensure that this dynamic would define our every circumstance. On the surface, at least, I *was* right, usually, and he was usually wrong. I made a point of this, and in fact we both did: it took seamless collaboration for our marriage to become so tidily disastrous. If we’d married other people, we might each have had to evolve. But as it was, we were lethally suited to confirm for each other the personas we’d learned in childhood.

We like to say we’re mostly over that pattern these days—the days that I’m writing this book. A recurrent conversation: Henry wonders how we could have fought so much all those years ago, when we hardly fight at all anymore. Then I disinter a few old, painful details, and the past seeps back into hearts we thought were watertight by now, and we grow uncomfortable and mute. For eight, nine years after Hannah’s death, we never, together, returned to those days, not even the happier ones. Instead, I soon learned to steer that wayward conversation quickly back to solid, arid ground. From an essay I wrote in 2008:

I thought we would grieve together, help each other through, have long talks and crying sessions, lay flowers at the grave. But it didn’t turn out like that; I’m not sure why. It seems [Henry] needed to keep quiet. Every time I tried to talk about Hannah, the air in the room seemed to thicken.

It’s only lately that the pattern’s been changing. Some ten years, now, since Hannah’s death, Henry’s reading these chapters as I finish them, and for him they seem, somehow, to declaw the past. His range of memory widens beyond visceral flashbacks of horrific moments to a larger, more inclusive picture—a gestalt, perhaps—of our life back then. It’s become his ordinary business, lately, to compare my version of events to his own, and sometimes the process captivates him, in part because his memories are often quite different from mine. So maybe it’s

true, this idea I keep hearing from people who know things: that writing or talking or maybe even reading about your own grief helps heal you, helps you find that illusive ghost they call “closure.” Maybe so. It seems to me right now, and may always seem to me, a bit too soon to tell.

The thing that changed the game for us, in the late nineties, early 2000s, was that after about a couple of years of blissed-out escapist revelry, my Prozac called it quits. I could feel myself slowly sinking, and with the help of various doctors I tried everything to prevent it—raising the dosage, adding other drugs, dropping it completely and changing over to Zoloft, then Paxil, Wellbutrin, Lexapro, Celexa, and on and on. But no matter what I did, I kept plummeting, fast and deep. I was no longer so implacable around the children. I was gaining weight again, I was getting so distracted and dull-minded that it wasn’t really safe for me to drive anymore. And yet of course I did drive, because I had to, and sometimes as, driving alone, I approached an overpass, I would wonder quite suddenly and casually what it might be like simply to veer the car to the right, careen into space, crash onto the road down below. I floated listlessly through stop signs, missed turns, and acquired a tendency, especially on highways, just to keep driving, blankly, blindly, until at some arbitrary moment I might shake my head awake and turn around again toward home. Along these same impassive lines, I remember once carrying a basket of laundry up the narrow steep stairs of our basement when, made clumsy by the bulky weight, I began to fall backward--then paused before grabbing the handrail, using the millisecond that followed to wonder, in dull curiosity, what would happen if I simply let go.

My “breakdown,” as we ended up calling it, didn’t happen all at once, but over time. And all through it I was in therapy, endlessly talking life through with several kind, insightful people who were of no real help whatsoever.

By 1999, Henry and I had more or less separated, though he was at the house so often that I’m not sure Becky, about eight by then, even knew it. It had happened like this—not as the direct result of the night I describe in my diary below, but of many episodes like it, over a period of years:

The mistake I made, on Friday night as we were sitting listening to Sinatra and the kids were asleep and it was only nine o’clock and it was all romantic and cozy and we were

alone, was in bringing all this up [his difficulty in coping] with him. Not good timing. I ended up saying that I was so tired of it, and that he must be tired too—tired of my wanting more more more from him, tired of my constant edginess around him, my distrust and resentment. We'd spent a pleasant afternoon with the kids, in Hannah's room, lounging with them both on the bunk beds, just lying around and playing while the sun streamed in through the big windows, and it was so lovely, but it reminded me with a start that this was the first time I could remember the four of us being together in one room and there not being any dread to it, the first time that Henry didn't seem to mind being there. And then I was conscious of the tension I still felt—how ready I was for his mood to turn black.

So here I am saying all this while Sinatra's playing—Sinatra being our signature foreplay music, of course. We end up talking about separating. I'm not sure how we got to that idea. It seemed to come up naturally. Yet of course he's devastated even to hear me mention it. The upshot is that we seemed able somehow to leave it all dangling that night, but the next morning I woke to find him angry and hurt, and I ended up apologizing for having hurt him, but I couldn't make myself add my usual, "Let's make it work, darling, I must have been a fool." No, I just left it all hanging. Where it still is—hanging. I don't know what I want to do. At least this time it's not about anyone else. Really, I can't think of any set-up that would turn out well, any relationship that would make life work, even if I squint away the harshest bits of realism. I can't decide if I'm being incredibly stupid for being dissatisfied with the best husband I could ever hope to have, or incredibly stupid for having stuck around and being so unhappy for so long. All I know for sure is that I'm incredibly stupid, which for now must be knowledge enough.

By the spring of 1999 I'd found Henry an apartment, where he spent his nights—and, I think, pursued his love affairs—for about six months. As the millennium turned, we bought him a small two-bedroom house six or eight blocks away from ours. Houses are cheap in Butte. This one cost \$35,000, most of it given to us by Henry's parents, to whom we described it as a "respite house," for one or more of us to escape to when the stress of living with Hannah got to be too much. Henry still spent most of his evenings and weekends with us, but now he had that house to rely

on. He slept there every night, and, when things got especially hard at home, he would head there right after dinner. I'd often *send* him there, as I recall, because it meant putting out fewer fires.

We talked about divorce, which he adamantly didn't want, and not merely because of his perennial fear of lawyers, I guess. I didn't want it either, really, but I pursued it, I learned how it worked, I had an expensive first meeting with a divorce lawyer. At the same time, I knew well enough by then that all versions of love, and not just ours, are tricky and flawed. And I was struck—shocked, even—to discover that, despite all his years of ambivalence, Henry really and truly wanted to make a go of the marriage. So we spent the next couple of years in a state of limbo, made easier to handle because of the “respite house.” Henry and I eventually created a schedule that allowed me to stay there instead of him some nights, and, especially as my mood sunk lower and lower, that reprieve felt not just soothing but necessary. By then my psychiatrist had suggested I check into a sort of halfway house for lunatic women—or however you'd label the sorority I belonged to now—a local refuge called “Silver House.” But I knew I could never be so cut off from my two girls, and besides, I had the “respite house” to go to when I needed it.

“If recollecting were forgetting”

I pause to recoil from a line in that last chapter: “By 1999, Henry and I had more or less separated, though he was at the house so often that I’m not sure Becky, about eight by then, even knew it.”

What foolish denial that is. Of course Becky knew there was trouble. I still have the little purple sticky note--a make-believe letter she must have written sometime during the time that Henry and Lily, one of our babysitters, fell into their year-long affair. “Dear Henry,” it reads, in Becky’s eight-year-old’s scrawl. “Will you marry me? Love, Lily. P.S. Don’t tell Nancy.”

For the first time since I found this note—between couch cushions, probably, a couple years after she wrote it—I dare to show it to Becky, who’s now in her early twenties. Perusing it in serious wonder, she doesn’t remember having written it, let alone having known about the affair.

Then I remember, out loud for her, another moment, when, at about the same age, she mused, in a tone of impartial curiosity, “It seems like Dad’s in love with Lily now, and you’re in love with Eric.” Becky was wrong about Eric, of course—he was only my very good friend, to whom I often talked on the phone. But that’s hardly the point, I suppose. I don’t know what I told her, in 1999 or so, when she said those words. Surely I said something along the lines of “Oh no, we’re all just very good friends.” But I didn’t pursue it further, then, because, so far as I could tell, she wasn’t disturbed by the clues she was finding, but merely curious. Curious, in particular, about this sweet and fancy new notion she’d only recently stumbled onto: “falling in love.”

Becky doesn’t recall this conversation, either. What she remembers most vividly about those days--I’m not sure. I’m especially unsure how she recalls her life with Hannah. She keeps those memories mostly to herself, I guess, or tells it to a diary or a friend. Or else sometimes she lays it bare, in poems like this one she wrote in high school:

Version

*Two kids in the bath again, me
just a smaller version of you.*

*If you cried, I’d sing like a miniature
mother, Moon Shadow
and Bye, Bye, Blackbird. No, I didn’t sing*

Bye, Bye, Blackbird then. Oh well, all memory is a lie.

You used to run from wall to wall of the house,

but did I really run after you?

I'm older than you now but I still

feel like a version of you.

That's an invention too, I can't say what you

meant in your silence. But if I could go back to

that bath and our feet could touch, and you

splashed – I know you would splash –

I would sing and sing until I lost all words.

There's this poem too, below, which Becky wrote a year or two later. As if it thinks I might forget, it reminds me again how little I knew of my younger daughter back then--and how little I know, even now:

Playlet

(The scene is a GIRL's bedroom. Lavender, love-themed—the work written calligraphically on the wall under the mural of a carousel horse. There are knickknacks, most of them broken. A porcelain Indian glued at the knees, an ugly yellow bird. There's a small portable TV on a table at the foot of the bed.

This is the play we have written: the MOTHER holding the GIRL on her lap on the bed. Offstage we hear the SISTER crying, running back and forth on a creaky floor, banging her helmeted head against the wall.) GIRL: What if she comes in here?

MOTHER: She won't.

(She doesn't. This is the play we have written.)

But the SISTER barges through the door, tears down the set. She doesn't acknowledge the audience or pretend that she can't see them. She grabs her MOTHER by the shoulders, pinches her arms, tries to bite her neck. The GIRL screams.

(The scene is still the GIRL's bedroom, the next day. The MOTHER is screwing a lock on the door. Just a thin metal lath that wouldn't keep anyone out who really wanted to come in. The GIRL will use the lock for years. When she's watching TV, when she'd doing long division at her desk, when there's nobody home, when her SISTER is dead, when the play is over.)

“Faith is a fine invention”

When Hannah was ten or so, I drove with her and Becky the three hours to Billings, Montana, to a business whose name I can no longer recall—a two-room office run by a chipper, middle-aged woman named Kate. She was a specialist—“certified,” she told us meaningfully—in providing an autism treatment called Auditory Integration Therapy. AIT, the brainchild of a French doctor named Guy Berard, became especially popular in the US after the success of Annabel Stehli’s 1991 memoir, *The Sound of a Miracle: The Inspiring True Story of a Mother's Fight to Free Her Child from Autism*.

Just as Stehli’s website promises, the book tells “the riveting story of her daughter Georgiana’s triumphant progress from autistic and functionally retarded to gifted.” AIT is a simple, ten-day “intensive listening program” meant to normalize sound sensitivity, and it’s supposed to help not only people with autism or Asperger’s syndrome, but, as I gather from AIT’s current website, with a cornucopia of other ailments, including traumatic brain injury, attention deficit disorder, dyslexia, anxiety, depression. Since I’d often noticed a hypersensitivity in Hannah’s hearing—e.g., her reaction to that high note in the Kathy Mattea song—I made an appointment.

We spent two weeks in Billings--and that was supposed to be enough, with no need for booster sessions later. For half-hour intervals, twice a day, five days each week, Hannah listened through headphones to a carefully chosen hodgepodge of “specially filtered and modulated music with wide frequency range.” It’s a harmless enough procedure, I thought and still think. Keeping the headphones on Hannah was tricky, of course, but she got used to them eventually, and didn’t usually seem to mind just sitting there in the AIT office, rocking, listening, jabbering, for the modest duration of half an hour.

In between sessions, the three of us had what seemed an endless amount of time to kill. Some of it we spent in our motel room—the two girls leaping from one bed to the other, the TV resounding with nonstop Nickelodeon, Hannah forever pulling down the shower curtain and me forever hanging it back up. We spent hours every day in the hotel’s indoor pool, which Hannah loved so much that, one afternoon, as we walked past its doorway in our street clothes, she made a sudden dash, and flung herself into the deep end. Naturally—since as far as I knew, Hannah

couldn't swim—I jumped in after her. In the middle of the pool, she was flailing and sputtering, but somehow she remained delighted, not at all afraid. She had such a wise body, you see, such trusty instincts that, if I hadn't been there, I think she might simply have learned how to swim right then and there, on her own, and done just fine. Or maybe not. At any rate, she welcomed my arms around her waist and clung to my neck as I pulled her poolside. Once there, it seemed that her water-soaked clothes and shoes made it hard for her to climb the metal ladder, or maybe she just wanted to stay in the pool, I don't know. I tried to haul her up and out myself, but couldn't manage it alone. Becky, meanwhile, looked on from the dry concrete deck, in mute bewilderment, and at the age of five was still a bit too shy to go off and ask the front desk clerk for help. In the end, I flagged down two passing hotel guests, who rescued us.

Every day, in Billings, we went to public parks and fast-food play lands. Hannah wowed the locals by perching, swaying, whooping, on the highest bars of jungle gyms. Once, she wedged herself into a rubber baby swing, and I recruited two fresh strangers to help ease her out. A couple of times, she crawled happily up into the tunnels that sprawled out in various directions like a drunken spider's web across the ceiling of a Burger King play land, and in a few minutes crawled out again, all the more exultant now for having stripped herself of her cumbersome clothing.

It was all so hit or miss, and you never knew when Hannah might explode. But we made it through the two weeks, through all the head-phoned sessions, and in the end, as I wrote a check for \$700 and thanked Kate for her patience, she told me, "Sometimes it doesn't kick in right away. Just give her a few weeks and see what happens."

So we did that, we waited. And nothing, so far as I was ever able to tell, came of any of it.

As I read about AIT now, on the internet, I see that, despite the occasional anecdotal miracle, the treatment has been pretty thoroughly debunked. So have several other therapies I put Hannah through in those days, or else tried to implement but soon lost patience for, or else endured the guilt that came from knowing the treatment was out there but feeling too weary, and later on, too jaded, to pursue it. In 1998, for instance, NBC's *Dateline* ran a story heralding secretin, a hormone extracted from pigs or else made synthetically, as the latest autism breakthrough. The report, backed by a dozen miracle stories, declared that injections of secretin might improve

autistic children's alertness, increase their eye contact, expand their use of language. I remember how, on reading this, I more or less begged Hannah's doctor to try secretin out on Hannah, but of course it was no use. "The evidence isn't in yet," I heard for the hundredth time. And the doctor, whoever it was at the time, turned out to be right: secretin was another fizzle. Double-blind studies have confirmed, again and again, that it's no more effective than a placebo.

Another intervention we tried was facilitated communication (FC). An autistic person points to letters on a keyboard, while her "facilitator" keeps a light hand on her pointing arm. This simple touch is meant to provide not just physical help but "moral support." Many parents, in the mid-1990s, began to swear by FC, as their formerly voiceless children began suddenly to type out whole sentences, express complex thoughts and emotions, write heart-rending poetry about their poignant young lives. But it wasn't long before a few unlucky parents had their children taken away, endured Kafkaesque court trials, were sent to jail, because their newly facilitated children had begun typing out lurid tales of sexual abuse. It took forever (or so it must have felt to these condemned parents), but, once simple, objective tests were performed, it turned out that, all along, it had been the facilitator doing the talking, not the kids. Subconsciously, for the most part, the facilitators demonstrated the sort of "Ouija effect" that I remember well from my childhood--when, for instance, our own family Ouija board predicted with flinchless clarity that the Green Bay Packers would win the first Super Bowl.

Yet plenty of parents still believe in these discredited interventions, just as many still think that babyhood vaccines caused their children's autism, though the evidence against that notion is by now overwhelmingly clear. Meanwhile, new hopes spring up like rabbits: sensory enrichment therapy, transcranial magnetic stimulation, antipurinergic therapy, epigenetics. Bumetanide, suramin, rolipram, arbaclofen, vasopressin. Today, as I read internet articles about the latest "breakthroughs," I can't help but feel, in the pit of my stomach, the stirrings of an old, unmoorable longing. If Hannah were growing up now, I'd surely be researching these therapies so I could bring them up at next month's parent-teacher meeting. I'd be scrawling out the names of these drugs for next week's neurologist appointment. My hope would flutter skyward no matter how hard I tried to tamp it down. At the same time, my throat would tighten—for it tightens even now, as my web-search of "autism" plus "hope" yields 43 million links—with an attendant spasm of dread. I'm overwhelmed by the sheer number of new hypotheses, not to

mention their obligatory fanfare, their certitudes tinged with provisos, the attachment of that hollow word “promising” to each therapy in turn. Saddest of all, as I keep reading, is a trend that’s new to me: the ferocious tribal wars—“to vax or not to vax,” lately, or the growing “disability-versus-difference” debate--that parents, or autistics themselves, wage, most often against each other, in the commentary sections.

And this, for all I’ll ever be able to tell, is what hope looks like, at least when it comes to autism. The bright half of a false duality, hope rises from a desperate parent’s denial of despair. Over the years, therefore, I’ve had to learn, the hard way, to believe in neither thing—no despair but no hope either. Instead I seem able to engage with the world only as it presents itself right now, with whatever might be tangible or provable or present. It’s my life’s deepest lesson, so far, I suppose—this surrender to the starkly here and now. Still, I don’t mean to proselytize my belief in unbelief. If I did, I’d steer you to well-tested therapies like Applied Behavior Analysis, and to no-nonsense websites like templegrandin.com and autism-watch.org. As it is, I let go the effort, for I can’t help but suppose that, if you’ve come this far, you’ve probably already been just about everywhere else already.

“As imperceptibly as grief”

Diary entry, July 7, 2002:

When I say goodbye—when I try to say goodbye—they put their arms around me, one from one side, one from the other. And they cling there. Henry says, Okay Beck, here’s the plan—we don’t let go and she never gets away.

It takes such courage to let me leave them—I must have done something wrong. It should be easier than this. Their lives shouldn’t suspend themselves in midair when I’m out of sight. It all makes me very nervous—I hate the goodbyeing. The long drawn-out process, the hug I have to wrench myself away from, the sad faces, hurt faces as if I’m betraying them by wanting something separate. I can’t walk into the room without their watching my every move. Today Becky tells me her latest tale of woe. Then Henry walks in and says, “When she’s done complaining to you, I get to be next.”

It was sometime around the turn of the millennium that people started to worry about me. I was something of a wreck by then, and it showed in the way I looked—gaining weight, wearing stained and shapeless clothing, not bathing. My hands were often shaky and my voice had a little quaver—and the funny thing was that at first I thought I must be just *pretending* to shake like that, putting on an act to gain sympathy. But as time went on—as it kept happening more and more, even when I was alone—I decided my symptoms must actually be real, and even as they hampered me, at the same time I found them odd and interesting. By then I’d even developed a facial tic that was becoming more and more conspicuous. At the sound, or even the memory, of one of Hannah’s cries of pain, my left eye would wince, the left side of my mouth would shift into a grimace, and, over time, as the tic grew stronger, my whole head would twist leftward, as if I’d just been struck on the right cheek, and would quiver there for a second before facing front again. (If I think about this very much now, the twitch comes back—you should see me at this very moment—but, luckily, that feels interesting too.)

Around this time, Family Outreach assigned a new manager to our case. Our original case worker, Carolyn, had been visiting us every week for over ten years now, since Hannah’s initial diagnosis, and she was a lovely woman—supportive to all of us and wonderful with Hannah, and able to find us an unconscionable amount of hard-earned taxpayer money for respite, books, toys, conferences. Still, when I looked back, I could see that Carolyn and I hadn’t really

accomplished anything else together. By 2002, moreover, we were both running low on energy and ideas, and our meetings had become sweet but pointless.

For many years, as I've said, my friends and family had been oh-so-timidly hinting that we might all be better off if we could "find a place" for Hannah. Half the idea was that Hannah would be better off somewhere where people knew best how to teach and treat her. And the other half was that it would be "triage"—that we could save Henry, Becky, and me only by letting Hannah go. I could never bring myself, throughout Hannah's life, to consider that second bit of reasoning, could never think of Hannah as if she were some sort of gangrenous limb to be severed if you wanted to save the rest of the body. But I could go along with the first part—for surely there

were places where people could deal with Hannah better than I could. That shining expert must be out there someplace, I thought, what with the world being so vast and amazing and all. So over the years I'd done the research, I'd sent away for brochures and studied them carefully. Most of the residential schools I discovered were prohibitively expensive, and none were close by. But I did find one, well-recommended school in rural Pennsylvania that, in part because it was largely staffed by volunteers, charged only \$30,000 a year. (We couldn't afford this either, of course, except, perhaps, with the help of Henry's parents and/or the state of Montana.) Thus, in the summer of 2002, during another trip to the east coast, Becky and I drove six hours, from Queens, to tour the place.

It was a farm, really—a small, working farm where chickens strutted freely and students helped gather the eggs. Kids also helped tend the big vegetable garden. There was also a cow or two, I think, and in general the campus was rustic and soothing, in the middle of a beautiful nowhere. Hannah would have liked living there, I think, with all that room to wander, plus a swimming pool, a gym, and dozens of sprightly saints who would devote themselves to her care. Becky and I toured the classrooms, the play areas, the gardens and barns. I talked to teachers, therapists, residential managers. We visited cheery houses where students and volunteers lived together in groups of ten or twelve: living rooms with ceiling fans and afghan-strewn couches, walls adorned with home-sweet-home embroideries. Kitchens that shone with fruit bowls and breadmaking machines, with refrigerators all but obscured by art projects, alphabet magnets,

chore charts. Long wooden dining tables where students and teachers ate together the food they'd helped gather and prepare.

It was all quite lovely, really. Still, I didn't know—the faraway-ness of the place made me hesitate, and the long waiting list to get in made it seem a pipe dream anyway. But the deciding moment—and this says nothing about the quality of the school, which, as far as I could see and had already read, was excellent—the moment that struck me most viscerally happened as Becky and I were walking the grounds with our tour guide. On the back steps of one of the classroom buildings a teenaged boy, just a year or two older than Hannah at the time, was standing—bouncing, really, rocking his body back and forth, pounding the whitewashed hand rails with his open palms, and screaming loud and endlessly. Our guide explained to us, in what I want to call a tone of nonchalance, that this was a good thing. The boy had made such progress, she said. He used to have these fits anywhere, anytime, and naturally they were very disruptive, but now he'd been trained to go out onto the back steps to rock, pound, and scream. And, yes, it *was* a good thing—I saw that then and know it now—but it also served to drive the point home to me: that this place, maybe like most places, was the setting for mostly minor-key miracles.

I felt a similar qualm a few months later, when I toured a school for autistic kids in Denver, Colorado: maybe eight students per classroom, each one of them shouting, lunging, overturning tubs full of crayons. This chaos—familiar to me but eighty times crazier when multiplied by eight—made me feel suddenly grateful that Hannah was the only autistic child in her classroom in Butte, and that her classmates were almost always cooperative souls not prone to fury. There's something to be said, I guessed, for being the most hard-to-handle kid in the class—at least she didn't have to *compete* for that dubious, attention-pulling distinction.

There was a facility for addled teenagers (though I don't suppose “addled” was their official classification) in Billings, and on someone's dumb advice we brought Hannah there in 2003. We were told the doctors would observe her carefully, adjust her medications, come up with bright new ideas. We brought Hannah to Billings by ambulance, because it wasn't safe anymore to take her on long drives in the car: on a recent trip home from Helena she'd started strangling me from the back seat, and I'd had to pull over at a rest area, get out of the car, sit on a bench, and watch blankly as Hannah, still in the car, raged on and on, until eventually she wore herself out.

The Billings facility was, as I recall, a cold and awful place. When, after half a day, Hannah was judged to be a danger to the rest of the population, the staff locked her up alone in a padded room. The doctor who was supposed to study her case was out of town that week, and his substitutes were clueless, while Hannah's other attendants seemed undertrained and nervous-and maybe, I got the feeling, a bit rough on their clients. Hannah stayed in that place for two days before we couldn't stand it anymore. We signed her out, and an ambulance brought her home again.

The case worker who took over for Carolyn was named Dori, and she worked with us for only a few months. Nevertheless, in that brief time, she revolutionized our lives.

“The blunder is to estimate”

Throughout her teenage years, Hannah was big for her age, and very strong. In the journals that passed back and forth between school and home, her teachers and aides began to document, as specifically, as scientifically as they could, the number and ‘category’ of her outbursts, then to translate the data onto roller-coaster charts. More than ever, they were desperate to find a pattern to it all—to see if she was more likely to get upset during, say, a particular phase of her menstrual cycle, or when she hadn’t slept much the night before, or at a certain time of day, or when she was hungry, or when the moon was full. For the purpose of such documentation, it was no longer enough to comment that Hannah was “pinchy” or “grabby” or “throwing a fit.” No, it was time to “quantify” these grim events, Family Outreach had decided, so they’d compiled an official list of Hannah’s “behaviors,” which included Pinching, Grabbing, Biting, Charging, Head Banging, Hand Bending, Arm Squeezing, Pushing, and Blocking. (“Blocking,” according to the list: “using the body to prevent escape or to intimidate with threat of injury.”) Accounts of Hannah’s daily activities thus became litanies of dates, times, and totals, in the punctilious manner of a child’s confession to a priest: “10:55–Hannah pinched me 6 times, bent my hand back 19 times, charged at me 15 times, head-banged 2 times.”

Looking back over these journals now, I notice, between flinches, the rarity of an entirely “good” day. Maybe twenty such days, all together, leap out from among three or four years’ worth of junior high and high school journals. Their summaries tend to be brief and undetailed: “Hannah was in a great mood today. She did everything that was asked of her.” Still, you can often hear in them a murmur of giddy relief: “Hannah went swimming this morning. She did very well. The rest of the day was awesome.” “A great day. No aggression at all!” Entirely “bad” days are more common, for sure, but most days are a hybrid, up and down, up and down, and their entries entail the longest paragraphs:

Hannah charged me 3x on the bus this morning [Hannah’s shadow, Sue, wrote]. Bent finger 3x. Grabbed 3x. When we got to school she grabbed me at her locker and bent fingers 1x. She was okay until 11:10 when she charged me and the gym teacher 6x. Bent finger 10x. We got her back into the classroom at 11:25. We went to lunch 11:30. She charged 1x on the way. In the lunch line, she had severe outburst. Charged 2x, bent fingers (severe) 8x, grabbed 3x. We had her sit at the table for a few minutes so she could calm down. Within 2 minutes she started head-

banging 20x, grabbing 10x, bending fingers 20x. We got her up to go back to lunch line and fixed her lunch. She ate and washed her lunch table okay. Came back to class, she rode her bike well without trouble. At 2:00 she charged me 1x, bent fingers 1x. At 2:25 Hannah started to whine. At 2:30, gave her 2 Ibuprofen. She took out her trash at that time. It is now 2:40 and Hannah is resting in her chair.

All of us, by now, were meticulous detectives, scouring each day's details for clues and causes. Maybe she had migraines? An ear infection? PMS? A urinary tract infection? A twisted ankle? She was shaking her hands a lot—perhaps they felt numb? Was she getting enough for breakfast? Was she getting enough sleep? Did her medicines need adjusting? One of her breasts was slightly larger than the other—did that mean anything? (No.)

I found myself then—as I find myself now—merely skimming each day's journal entries, squinting away grimness and lingering over delight: “Hannah was happy and playful. She played outside and on her bike. She was very cuddly and wanted lots of tickles.” “Mellow and happy all day. She would jump at us, but no attacking.” Still, one fact was hard to avoid: Hannah's rages were “escalating,” as everybody put it. At home it was the same—her fits grew fiercer, more frequent, while her “mellow” moments dwindled. More and more, I spent my days listening for alarms and putting out fires. I grew so used to my arms being covered in bruises and bite marks that I only noticed them when someone else pointed them out. But the change that hit hardest came when Hannah started going after nine-year-old Becky, who took to hiding in our gloomy basement whenever tensions flared upstairs.

The year 2002 was a time of last resorts, and while I still couldn't really see that, our new case worker, Dori, could. Within a week of working with us, she began to look into the possibility of a group home for Hannah, but soon discovered that, for now, this was a dead end. The homes with vacancies were all in tiny towns—Shelby, Hardin, Broadus, Glendive—tucked away in far corners of the state. Moreover, at fourteen, Hannah was commonly considered too young for such a placement—or, if not too young, too dangerous.

Dori's next suggestion was that Hannah become a “ward of the state”: we would sign away our rights to her, and she'd be placed in a foster home. For me the notion felt surreal, and I remember having to pause for a minute to realize it wasn't a bad joke or, worse, a test of my

maternal love. To say I found it “unthinkable” makes me sound noble, I suppose, but that wasn’t it at all. No, I simply couldn’t force my mind so much as to imagine giving my child away. No matter the cause or consequences, the thought of surrendering Hannah remained always, quite literally, beyond my ability to *comprehend*.

Then Dori had her brainstorm: with added funding from the state, we could move Hannah into our ‘respite house.’ It would become a sort of group-home-for-one, staffed by a revolving army of caregivers who would tend to her from the time she came home from school until, say, eight or nine at night, when either Henry or I would drive down to spend the night with her, alone, and get her ready for school in the morning.

And that’s, in the end, what we did. To put the plan in place required work, time, training, and probably a wheelbarrow full of taxpayer cash. It required sweeping adjustments and perpetual fine-tuning. The move began as an experiment, but afterwards revealed itself as a turning point, as more and more of Hannah’s care was delegated away from me, as daily decisions became, increasingly, the duty of strangers, instead of my own.

I couldn’t see any of this then, but fretted, instead, over details. There was no tub in the other house, only a shower, so how was Hannah going to take a bath? Water was one of her favorite luxuries, after all. At home, she’d take three or four baths a day, and would run the faucet herself—filling the tub till it overflowed, its water trickling through cracks in the living room ceiling. At this point (or, with any luck, *before* this point) I’d call to her, up the stairs, “Turn off the water!” And then, to my everyday amazement, she would actually do it. Command and response, cause and effect. And how the fact cheered me—that Hannah could and would follow an instruction from me. From the living room I’d hear the water’s roar grow suddenly still, and it felt miraculous—a breathtaking moment of connection between us, a thrilling glimpse of “normal.”

Bathtub or not, Hannah liked the other house. After a week or two, in fact, it seemed she preferred it to the house she grew up in, and sometimes after being with us, back on Quartz Street, for a few hours, she would walk out the front door on her own, and wait in the car to be driven back “home.” I don’t know why she felt this way. Everybody talks, after all, about how hard it is for autistic people to adjust to changes in routine, and in some ways this was true of

Hannah. But when she moved to the respite house, she adjusted quickly and easily, and it makes me think—suddenly, in the here and now, I mean—that maybe she felt relieved to get away from us all at last, that she felt the tension too, perhaps, felt it smoldering, flaring in us just as surely as we felt it in her. Certainly, her caregivers, working their four-hour shifts and then heading home, were at this point capable of far more grace and patience than Henry and I could dredge up from within ourselves. Then too, the respite house was quieter than ours, and afforded Hannah more space and privacy. She might also have relished the fact that I hadn't put locks on everything there—cupboards, refrigerator, rooms—as I had at her 'old' house. I don't know. I hesitate to supply my own reasons for Hannah's response in the same way I tend to dismiss the many reasons others ascribed to her over the years. I don't, in the end, know why she loved the other house, but only that she did.

“The feet of people walking home”

The problem with getting help is that you get used to it. I was the marathon runner who collapses on crossing the finish line—oh, but of course this wasn’t the finish line at all. Witness this letter to a friend, after Hannah moved out:

It reminds me a little of a time during the week [in 1986] I watched my father die. I’d flown home from Virginia, where I was living and teaching then, and along with the rest of the family I worked day and night to take care of him, to get him through his last days as peacefully as I could, and I felt privileged to have the chance—to massage his shoulders and comb his hair and to ask him, during lucid moments, to talk again about olden days. And then one night the hospice nurse volunteered to watch him while we all went over to my sister’s house to play games for a few hours, and I remember I felt reluctant to leave him, kept saying I didn’t need the respite, that I wouldn’t mind staying home in case Dad needed me. Still, the nurse cajoled me, and I went. Then once we got to Lori’s house, and we’d been playing games a while, and even laughing and joking as if it were just another ordinary family get-together, there was a moment when we all suddenly looked at each other, and it seemed to hit us all at once: how relieved we all felt in this moment, and how much we dreaded going home again to all that heavy grief.

I couldn’t go back. Henry and I were supposed to take turns staying the night in the other house with Hannah, and every time my turn came up, I’d move through the day in a growing cloud of panic, so that by the time nine p.m. came around I was twitching, hyperventilating, and the only thing that kept me from having full-blown anxiety attacks was that I didn’t want Becky to see them. Once I got to the other house, things might go fine. Hannah might even be asleep by the time I got there, and in any case she was bathed, brushed, and dressed for bed. No matter how awful her day might have been, by nine p.m. she was often ecstatic. She’d squeal and rock to Wee Sing videos, her hair slick and wet from her nightly shower, her cheeks flushed with scrubbing. Affably, each time I asked her to, she’d leap to her feet again, then turn and pull her long-suffering La-Z-Boy a few feet forward--away from the wall, already cratered, behind it.

A hundred other nights, she flew at me in rage. The toughest moments come back to me now in flashes, a series of graphic scenes: locked inside the respite-house bathroom, I sit on the floor,

bracing my back against the flimsy door as Hannah hurls herself against it from the hallway. The wood arches inward, a wind-billowed sail. Knowing how soon it might fracture, I scan the room for something with which I might deter attack. Shall I throw a towel over her head? Or fling a dixie-cup's worth of water in her face? If I sprayed air freshener at Hannah, would it hurt her eyes? Would it even slow her down? Would it only make her madder?

One night, I sat smugly on her living room couch, sure that at last I'd found a foolproof defense. By leaning recumbent against the corner cushions, I thought, I could stave off Hannah's lunges *with my feet!* And then, of course, that didn't work either—she simply bit my big toe, so hard that by morning the nail had turned black. *I'll just wear shoes next time!* I must surely have thought at that point, for these were days of endless experimentation. All theories got tested, all options got tried. Wearing shoes, I'd soon learn, was no protection at all. Nor did it help

to curl into a ball, the way you're supposed to do with bears. For Hannah's resolve, in these ragged moments, was undauntable. So you did what you did. You stayed in the room with her for as long as you could, then scuttled off to hide behind some weak barricade, waiting out the storm.

At the tenuous close of every night at Hannah's house, I'd lock myself in my bedroom, so that she might not attack me while I slept. I'd dial high the volume of my white noise machine, so that if Hannah began wailing in the middle of the night, or if, made drunk by her own vivacity, she turned the TV on loud and rocked herself crazy to Disney-channel cartoons—or, indeed, if anything, anything at all, happened in the world beyond my room—I might somehow be able to sleep straight through it.

Yet I remember many good times, times of sweet connection that—for better, for worse—resurrected my trampled hope. From an email to a friend, May 13, 2003:

I spent a lot of time with Hannah this weekend, and it was lovely. She's been doing very well lately, and we had some very sweet, affectionate times together. She wanted me to hold her, tickle her, massage her shoulders, and generally to roll around on the bed with her the way we used to do when she was little, and meanwhile I talked to her about those old days, the sunny room we spent a lot of time in then, the window we looked through, the games we played, the songs I used to sing. I know, somehow, that she understood a

lot of what I was saying, though I don't know how much. It all seemed to keep her very happy. She seems to love to be talked to these days, about anything at all, and she even loves to be asked questions, though for all but the simplest of them she has no way of answering.

In a letter from September, that same year, I write:

On Sunday morning she had me play a game in which we stood on opposite sides of a glass-paneled door, and put our faces against the glass so that our noses pressed up against each other, with just the cold glass between them. Then she pulled me to her side of the door and pressed her nose against mine without the glass go-between, and she seemed really excited by this difference in feeling, glass versus flesh. She sent me back, behind the door, and we repeated the process, two or three times—our cozy science experiment. And I don't know how to tell you how thrilling it all was. What seems to be happening, in other ways too, is that she's finally starting to discover her own selfhood—to get a sense of the boundaries of her body in space—and, from that information, to learn how to make more interesting, more profitable connections with the world. It's hard to describe, but suffice to say that autistic people often don't know where they end and the world begins, and these days I see Hannah trying to teach herself that, and reveling in her conclusions.

I think gently, too, of an early Sunday morning in the fall of 2003, when Hannah left the house in only her nightshirt, and raced away down the street. I quickly followed her, in my own nightgown and slippers, to her favorite park a block away. The day was warm enough for me to perch atop a picnic table there, pondering the anatomy of acorns, as meanwhile Hannah reeled, in her old rubber swing, from sky to sky. When she was ready, at last, to go back to her house, she nonetheless held back, frustrated, stiff, at the edge of the grass, and I remember, as well as any fine moment that day, the thrill I felt when, at last, I guessed the reason: that the pebbles and nuts dappling the sidewalk and street were too hard on the bottoms of her feet. I sit here thinking of that moment again, wondering if I can ever explain the joy I felt: the miracle, the bliss of discovering, at last, a problem I could actually solve. I took off my slippers and put them on Hannah's feet. She laughed—elated as if by a magic trick—and, happily, agreeably, we walked each other home.

“The past is such a curious creature”

Yet all the while, I was sinking lower, lower, and sometimes that felt distantly sad to me, as if I were watching someone else sink. I’d known her long and well, this feckless woman. A step behind, I’d lurched along each trail she’d taken. I knew well how she’d trusted—for the news had come straight from Jesus—that she could please the whole big world at once. Yes, but watch her cower now, so merely empty, merely frail.

I could still summon myself to life when I had to. I could do laundry, load the dishwasher, drive to necessary appointments. I could “be there” for Becky, could be sweet with her, attentive, and even fun—or at least that’s how I’m bent on remembering myself. But around Hannah I was ceaselessly anxious, even when a day was going well. I could hear her primal howls even when she wasn’t near. Even when she slept, or when I did. With only a blink of thought, in fact, I can hear them still, today.

I wonder now, to a degree I couldn’t then, at the anguish Henry felt as he watched me come undone. Our affairs were more or less over by now, and though we still talked of divorce, we never had much passion to pursue it. We didn’t fight so much these days, though part of him—ha, who am I kidding? part of me too—still sometimes wanted to. For him, he said later, our battles confirmed some trace of connection between us; they were, at least, a surefire way to rouse me from catatonia. Or perhaps I’m just projecting my own, more ancient feelings here, for my words echo precisely my memory of my early days with Henry: all the hammy melodramas I myself had staged, in the course of two decades, to lure my bored husband’s attention. As bad, I think, as it ever got: the Bob Dylan concert in Big Sky, July, 2003. We’d gotten overnight sitters—one for each house’s daughter—and had reserved a hotel room near the resort for after the concert. It would be the first night we’d spent alone together in five years, and our plan was to make the most of it.

Things got off to an ominous start. Alive, for the moment, and determined to sit close to the stage, I feigned a search for “friends” in the front row, leading Henry in zigzag through the compliant crowd. We were, all of us, wannabe hippies tonight, with our paisley picnic blankets, our sandals, our coolers abrim with goat cheese, prosciutto, Merlot. (Our own, less glamorous version: granola bars—one in each back pocket.) On the way to the front, we chanced upon Lily,

the latter of Henry's ex-lovers, before us this evening with her long hair flowing, her earrings gleaming in the lowering sun, her hand lightly brushing the hand of her shiny new fiancé.

I hadn't seen Lily in eight or ten months, and our last conversation had lacked a proper ending: she'd announced, over the phone, that Henry had been lying--that, weeks after he'd told me he'd broken off their relationship, he was still sleeping with her. Her tone had been bold as she'd let me know this, as if she thought it might make some difference to me. Some miles past caring, I'd answered with a tepid uh-huh.

Back to the concert. From my journal, July 31, 2003:

We settled in close to the stage, and then I headed back to where Lily was. I like the fiancé—the look of him anyway. He didn't say much but they looked 'right' together. The same age, for one thing—but not just that. They have energy, or something. They held hands, they were all flushed and beaming, they seemed to be looking out from a high perch that only they knew about. The summer afternoon, the meadow, the happy crowd—it was like the two of them were sharing a sweet adventure. I can't remember the last time I felt like that. Lily's like I was, like I am still. Smart mind, dumb heart. Anyway, I don't really need to be friends with her again, but I'm glad she's doing all right.

Back on our blanket, Henry was angry—not about seeing Lily again, I don't think, nor about my going over, nor even about her having a fiancé. No, he was just angry, I think, and it could have gone in a hundred directions. During the concert it got aimed at Bob Dylan, who was only doing “new stuff.” Who seemed to be hiding behind his electric piano. Who played his guitar only once. Who barely acknowledged the audience. And on and on.

After the concert, I couldn't find the hotel. (Missed a turn.) Meanwhile, there was a bottle of rum in the car, rolling back and forth on the floor of the back seat. I'd bought it just for the occasion—our first night alone together in such a long time. Sex was *de rigueur* tonight; hence the rum. It was just for me—Henry hadn't had a drink in a year at that point. But when I didn't respond much to his Dylan denunciations—for I've long ago given up asking any more of Bob Dylan than that he should always exist, please, in whatever form he prefers—and then, later, when I got us lost, he opened the bottle and started drinking straight from it “like a hired gun in a John Wayne movie,” as my diary puts it:

Meanwhile I'm trying to stay shut down, because I don't know what else to do anymore. I just kept driving, squinting for road signs. Finally, a little before midnight, I found the hotel. I put on my usual cheerful act for the desk clerk, of course, but I muted it a bit because if there's one thing Henry can't stand, it's when I'm nicer to strangers than I am to him.

When we got to the room, I had him go to the bathroom first, so that I could hide in there afterwards. Then eventually I got into my pajamas and buried myself in the bed. Henry ranted on, not about Dylan or even Hannah but about me by now—all my “running away”—and when I didn't respond, he pulled the blankets off me. When I still didn't respond, but curled up even tighter against the wall, my back to him, he went around the room turning on all the lights. Then he turned on the TV, crazy loud.

And that was what finally got to me. 'Cause it's one thing to make me miserable, after all, and quite another to disturb some hypothetical, anonymous neighbor. I turned the TV off; he turned it on again. Etc. And this might have gone on all night if I hadn't posited that someone was probably right this second calling the front desk about us, or maybe the police. So he kind of calmed down after that, and anyway it was way past his bedtime. The next time he went to the bathroom, I took back my blanket, wrapped myself up in it, gripped it like death. But that was the end—he didn't try to take it again.

A few days after the concert, we told the whole story to Jeff, our intrepid marital therapist.

“I thought about just leaving—driving home alone,” I said. “But I'd only have to come back to get him the next day.”

“What about going back down to the desk,” said Jeff, “and checking into another room?”

“Huh,” I said, and thought about it. “And pay another sixty dollars?” Jeff nodded.

“But the night was already half over.”

“And?”

“And so that would have been, like, fifteen dollars an hour.” I paused, then let out a laugh.

“You're not saying I'm worth *that* much, are you?”

“Success is counted sweetest”

2003 through 2005. I’ve felt too shaky, all these years later, to compile my own version of Hannah’s last three years. So I’ve spent the past many days *reading* the story instead, as recounted in a set of fourteen spiral notebooks filled with anecdotes supplied by the revolving team of caregivers who supported Hannah at home and school. There are, all together, twenty-three different chroniclers. Some disappear after a week or a month, and some serve to the very end. They write their daily paragraphs in disparate styles of penmanship that seem, over time, to confide the same aspects of their characters revealed by the words they use. Some styles are bubbly, chubbily ripe, with loops as round as apples or balloons. Some slant severely forward as if to brace against a headwind. Some, from a distance—with their tight, draftswoman printing, their geometry of lines precisely parallel or perpendicular—look like an impervious metal grid. Some are frantic. A few stay calm in spite of everything.

(And after a while you see that the only places you feel relatively safe are on the islands of balloons and apples. You find yourself relying on maybe seven such bubbly handwriters as you squint through the years—six young women, one young man. After a while, your breath loosens a bit when you reach their paragraphs, as you begin to understand that, no matter the day’s calamity, they’ll fare forth with grace, good humor, and love.)

There are sections in these notebooks that I haven’t read in several years. Many entries—at least half—I never even read at the time they were written. There are practical reasons for this, of course: caregivers retold each day’s events already, when they spoke to us at the beginnings and endings of their shifts. I always felt, moreover, so estranged from Hannah’s paperwork. How I envied the nonchalance of “normal mothers”—those not obliged to become technicians who analyzed and recorded their children’s every mood and move. For Hannah’s notebooks aren’t sentimental keepsakes—or perhaps I haven’t yet reached the transcendental moment when I can think of them as such. Instead, for right now, they serve as a sort of quasi-scientific “documentation,” a meticulous itemization of “behavioral data” in the hope of finding patterns of cause and effect.

They make for brutal reading. Even the happy times—and there are dozens and dozens—are so hyper-celebrated that, at the same time you feel overwhelmingly grateful for each exclamation point, you wonder at the *relief* each caregiver must feel to include quite so many:

March 25, 2003: *Hannah was in a very good mood today! She wanted to play and be tickled a lot!! She took a short nap before dinner. She tried to grab my arm once because she thought I was taking her dinner plate, but other than that we had a great day!!!*

It remained, forever, impossible for any of us to find useful patterns in Hannah's changes from day to day, or from month to month. But now as I read through these three years' worth of entries, some things do seem clearer. The first is that we should never have spent so much time worrying about her bowel movements. Ditto PMS, ear infections, weak ankles, migraines, and the fact that one of her breasts was slightly larger than the other. Moreover, despite my willed myopia, I can't help but notice how, over the course of these years, and despite all hope and toil, Hannah becomes less and less governable.

In the early-2003 journals, there's often a semblance of domestic order:

February 3, 2003: *Hannah was very happy tonight when I got here. Nancy gave her a haircut. She [Hannah] took a good shower at about 5:30 PM, and she helped me with dinner at about 6:30 PM. She was tired but stayed up and watched a movie. I gave her meds to her at 7:00 PM. She went to her room and was awake until about 8:00 PM. She seems like she feels better today but she never went to the bathroom. Nancy did change her pad as soon as she got home from school. She has not been passing any stools lately.*

There's also a point in nearly every day when Hannah thrills everyone. "She took a shower, and helped me with dinner," a caregiver will note. Or else, maybe, "She gave lots of hugs and wanted to play all evening." "Hannah picked up her toys when I asked her." "I saw Hannah sign 'no,' 'eat,' 'please,' 'yes'... I'm sure I will see more!" "She was really cooperative at school and here." "She is on the right track!!!"

There's another point, in nearly every day, when Hannah becomes "pinchy" or "grabby" or "grumpy," but can usually be soothed by food, music, a walk to the park. Hannah, in 2003, is sometimes "reluctant about going to bed" or "very crabby when she got home and throughout

the night. She was very distant and wanted to be left alone.” She might refuse to take her shower or to put her dishes in the sink, but she was, mostly, manageable.

Soon, though, both lows and highs grow more extreme. Some entries segue straight from disaster to miracle:

May 14, 2003: *Nancy and I took Hannah to the mall to get new shoes, and she was wonderful and happy the entire time! When we got home Hannah got pinchy and came at me a few times. When I tried to get her in the shower she got very mad and attacked me many times. She then started to cry. I asked if her head hurt and if she needed medicine. She clearly said ‘head,’ signed ‘hurt’ and signed ‘medicine.’ I gave her some ibuprofen. I told her that I would leave her room, but I would be back in 15 minutes. (I showed it to her on her clock.) I asked her if in 15 minutes she would get in the shower for me. She signed yes. And in 15 minutes she got up on her own and got in the shower!*

Another day might begin well and end terribly:

November 10, 2003: *Hannah was very playful and laughing a lot. She took a shower with no problems. I started to cook dinner, she did well waiting. I gave her dinner, then I sat down to eat with her. I asked her to slow down, then to use her napkin. She did all right with all of this. Then she started to eat very fast, putting 2 chicken nuggets on her fork at a time. I asked Hannah to only put one on her fork at a time. She jumped up (with the fork + 2 chicken nuggets in her mouth), grabbed my hands (while I sat in the chair next to her), pushed me onto the ground and bent my back into the chair. Finally she let me up. She sat back in her chair, grabbed my dinner and finished it off.*

By 2004, Hannah’s caregivers—still hopeful, still devoted—were covered in bite marks and bruises. Their fingers were swollen or sprained by Hannah’s bending them to the fierce threshold of breaking. For their own safety, they no longer worked with Hannah alone most days, but in pairs.

Meanwhile, as I read on today, the guilty egomaniac in me keeps searching merely for mentions of my own name:

October 9, 2003: *Today when I arrived, Nancy was already here. She had to come relieve Theresa around 2:00 because Hannah had “constant” aggressive behavior toward her.*

November 13, 2003: *Hannah’s had a great day. She has had a couple of episodes where she acts like she is going to seizure, then comes right out of it. I talked to Nancy about this, and she will talk to the doctor.*

January 22, 2004: *Hannah was limping pretty bad earlier today. So we called Dr. Graham for advice. So we took Hannah to the ER to check leg. Hannah was very cooperative the whole time. She was still laughing and playing with staff. Mom [Nancy] and Sarah took her home. Hannah was hungry. So Sarah went to the kitchen to prepare something to eat and then Hannah attacked Sarah by biting her on the hand. Sarah went to the ER to get the bite checked. She will fill out an incident report.*

I myself write only fifteen or twenty short entries in these three years’ worth of notebooks, mostly to announce medicine changes or to note, as if without exasperation, that the x-rays found nothing at all wrong with Hannah’s ankle. It’s no surprise, of course, that I don’t show up more often. I’m falling apart, after all. Still, it soothes me to notice that I’m still buying groceries now and then, driving Hannah to appointments, filling prescriptions, buying her shoes, writing checks to cover her school lunches, bringing over cookies.

It reminds me—and how often I still need such memories—that there were still sweet moments between us. That there remained, still, a few ways in which Hannah could count on me. I was great with her in hospitals, and could get her to sit still for the length of every blood drawing and blood pressure check, with a patience we’d both learned from all the teeth cleanings, eye exams, haircuts I’d coaxed her through, these many years. I sang her through a CAT scan once—me leaning over, lying half on top of her on the sheeted slab, her head in the big loud tube and my hands gently holding her shoulders down, both of us cozy under the same lead blanket. I sang Cat Stevens’ “Moon Shadow”—Hannah’s favorite song, and a salute, as it happens, to the benefits of ‘disability’: “And if I ever lose my eyes, I won’t have to cry no more.” It’s a perfect song, whose simple verses and chorus can be sung over and over without pause, like a hypnotic hymn, all through the thirty-minute length of a CAT scan.

One memory leads to another: a simple afternoon when Hannah was four or five years old. From the kitchen I'd entered the living room to find her sitting in her usual catbird seat, the newel post on the landing of the stairway. Gazing out the living room window, she was quietly singing "Moon Shadow" to herself. Her enunciations were slurry ("moo-sha, moo-sha"), but she had the rhythm and melody just right. When I heard her, I stopped stiff and still, the way you do when you spot a fawn beside the hiking trail. I held my breath as if to hold on to the moment too, as Hannah sang carelessly, dreamily, fascinated with the play of sunlight through the bright windows—for ten or twenty more seconds, then trailed off.

I never heard her sing again, but that is, and has to be, all right. After all, as Cat Stevens sings, in a tone of hard-earned relief: "And if I ever lose my mouth, I won't have to talk."

“My Life had stood--a Loaded Gun”

This morning you're writing a check, and it takes you five seconds to remember that the current year is 2016, not 2006. Lost in the notebooks, you slip into moments when you believe they're all still down there—eight blocks south and two blocks west of where you sit right now: Hannah and two or three of her young helpers, going about their businesses. They're getting dinner ready, or walking home from the park, or dancing to the Wiggles, honing the arts of both compassion and self-defense, and now and then noting, for the record, every up and down in Hannah's every day.

In this world a dozen years behind you, you note the budding of a little miracle. Oh, you could look at it another way, of course. You could see what happens now as loss. For you yourself are disappearing, bit by bit. See these posts from Sue, Hannah's shadow at school:

October 15, 2003: *Hannah has had a couple of episodes where she acts like she is going to seizure, then comes right out of it. I talked to Nancy about this, and she will talk to the doctor.*

October 18, 2003: *Hannah was a bit grabby today. No real aggression. We did not make her do anything physical because Nancy was to call us after she talked to the doctor. Have you heard anything?*

Meanwhile, who should be showing up in your place? None other than your husband. (I.e., Hannah's father.) On October 20, it's Henry who writes:

Nancy called Dr. W in Helena and he sent a fax to Butte High saying that Hannah can participate in normal activities again. It seems she doesn't want her breakfast, so I'll put it in her bag.

Thereafter, more and more often, *there he is*. He writes many entries himself—most of them scrawled (usually in pen, once or twice in crayon) during the early morning micro-seconds between Hannah's readiness for school and the arrival of her school bus:

April 3, 2004: *Hannah seems ok this morning. Had a little breakfast. I've signed and enclosed the Special Olympics form.*

June 13, 2004: *Hannah a bit grabby this morning, but not bad. Not interested in breakfast. Put some ointment on her chapped lips. She still has the cough.*

September 12, 2004: *Hannah's bloodwork came back from the doctor's, and all her tests came out negative.*

December 1, 2004: *Hannah was up a lot last night (much of the time very unhappy), so she should be pretty tired today. We'll buy one of the Butte High t-shirts. Size XL or XXL, I'd think.*

He shows up in the caregivers' entries too:

February 29, 2004: *Hannah had a horrible weekend. On Saturday, I was called in to help Val. Hannah had headbanged on the glass window in the door, which caused it to shatter. She also bit Val X3 really bad. I called Dad [Henry] to come help, and I took Val to the ER. (The bites were really bad.) Henry and I picked up the glass and fixed the window the best we could. Lisa came from Helena to try programming [DTT, or Discrete Trial Training, was our latest promising therapy], but decided not to do anything due to incident. Lisa also discussed changes in programming with Henry and me. Hannah persisted with her aggression.*

March 3, 2004: *Attention Jackie and Val—The glass people are coming to get an estimate on the broken window, and also the large window in the living room. Henry talked to them about replacing the big window with plexiglas due to safety issues. He is looking at house insurance to pay for the damages. Keep Henry posted on what the estimate is! Thanks!*

April 29, 2004: *At 9:15 last night, Hannah suddenly started headbanging in her bedroom X3. Henry was just pulling up to relieve me. She became extremely aggressive towards Henry and me. For about 30 min, she headbanged X30. She was very upset about something! Her face started bleeding, and I was unsure what was hurting. (Mouth?) She headbanged very hard against many things! It was very scary! Henry was hurtin'! It was a rough night for all of us—I left after about half an hour.*

And on and on. Below, my personal favorite:

November 19, 2003: *Henry got a urine specimen from Hannah this morning! This is great! Please keep working on the stool sample.*

The change took time, but Henry still remembers the moment he knew it had to happen. It was late in 2002, I think, at one of our quarterly “Child Study Team” (CST) meetings at Hannah’s school, the bunch of us settled around a long conference table in a meeting room just off the principal’s office.

Hannah was at the high school by then, so the chairs we sat on were all full-sized. In earlier days, stragglers had been forced to pull kid-sized chairs to the big table. (Once, Hannah’s occupational therapist presented her entire report while lying supine on a furry purple beanbag.) In those earlier days, we’d met in Hannah’s classroom, always a cheery place, with walls overwhelmed by color charts and calendars, illustrated alphabets, finger-painted sunflowers, doily valentines. By contrast, the high school meeting room served most often as a gallery for student art exhibits: cruel self-portraits, devastated landscapes, psychedelic women with snakes for hair, dead roses sprouting from a machine gun barrel. “Homage to Edvard Munch.” “Still Life with Skull.” How soon they pass, the carefree days of childhood.

How many people attended that particular meeting? A brigade, it seems. Hannah’s classroom teacher, her shadow, other classroom aides, her speech therapist, occupational therapist, district psychologist, school nurse, Family Outreach representative, district special ed director, Henry, me--our scribbled names crowd the signature lines at the bottom of the triplicated form. How official, how sacred such forms were to us. At the end of every meeting, we passed them around the table, like bread at the Last Supper, and everyone made at least a show of glancing through each section before signing off in approval. Even I did that, holding the collated document, feigning thoughtfulness, though in truth I would have signed anything by then. I no longer believed—not really—in the power of plans and programs.

Sometimes it seemed I was the only one who noticed that so many of Hannah’s “goals” kept repeating themselves, from quarter to quarter, year to year, again and again “unattained.” Take this standard ambition: “Hannah will communicate her needs.” I think a lot of us—even I, sometimes—were longing, even at this late date, for that Helen Keller/Annie Sullivan moment, when Hannah would simply *get* it, just like that, and then, ecstatic with epiphany, would

suddenly *beg* to know everything—*everything*--our world might have to offer. But in real life, neither signing, nor communication boards, visual schedules, choice charts, keyboards, flashcards, picture exchange wallets, nor any manner of pleading, prayer, praise, reward, or reinforcer—nothing we'd tried had ever tempted Hannah to add her own voice to the world's cacophonous chitchat. Hannah's goals were no longer academic but centered around practical skills and self-care. "Hannah will brush her teeth after lunch." "Hannah will wipe the cafeteria table." In these areas she was always doing "much better," it seemed, but none of them ever became her self-determined habit (except, of course, for toilet training—an epic achievement, never to be surpassed). Instead, every task required constant supervision, in large part because Hannah didn't give a damn about it, nor even the rewards that might accompany it. Oh, she learned it all, all right. She learned very well how to brush her teeth, comb her hair, use a napkin, place dishes in the drying rack and laundry in the washer. But all her life she neither understood nor seemed to want to understand why she (or anyone on earth) should find such activities the least bit worthwhile.

The goal we sweated most over, in Hannah's high school years, was often stated thus: "Hannah will reduce behaviors injurious to herself or others." Although Hannah's stalwart new shadow, Sue, took the brunt of Hannah's rages at school, sometimes no one there was safe: "Hannah went off on the bus severely. We had an evacuation for safety reasons." "She tried to grab at all of us." "She was so out of control that we had to remove the other students from the room."

Hannah's classroom, at least, was conveniently located: across the hall from the nurse's office, and next door to the machine shop, with its affable, burly shop teacher, who morphed into Superman whenever one of Hannah's helpers used the class intercom to "call a code." That's what they called it. "Mr. Cameron, code green," is how it went, I think, spoken as if non-desperately. (Code 'green'--with its evocations of springtime, leprechauns, Peter Pan—had a cheerier ring, I suppose, than code blue, red, or black.)

December 12, 2003: *Hannah did well on the bus ride until we got half a block from school. She threw a major fit, severely headbanging the window frame of the bus. She bent fingers 20X. We got her into the school and she pinched a teacher X2. She banged the front of her head on a table 4X. She whined and bent fingers X20. ... At 10:30 she charged at least 3X then took off to the lunch room. When she saw there was no food yet,*

she sank to the floor and banged her head X9. Bent fingers, grabbed 20X, pinched 2X. We called a code on her and several people on the team came down to help. Shani did the brushing joint compressions on her. She calmed down just enough to get her back to the classroom. Shani noticed that Hannah had blood on her head. She had banged enough to open an old scar. Shani cleaned it up and it's okay.

Caregivers, at home and school, were being trained in the Mandt System (which describes itself online as “a comprehensive, integrated approach to preventing, de-escalating, and if necessary, intervening when the behavior of an individual poses a threat of harm to themselves and/or others”). The technique we performed most often on my rampant daughter consisted of a tight bear hug from behind, with which we gently, firmly, pinning her arms to her sides until either she calmed down or the SWAT team arrived. (It never actually came to that.) The tallest among us had the easiest time with that hug: as your arms clenched around Hannah (“with dignity and respect”), she meanwhile pummeled you with the back of her head, and that couldn’t help but hurt. But if you were tall enough, her jackhammer skull rebounded, not so unbearably, against your chest instead of your chin.

I paid attention at the CST meetings, but after all these years I could offer only occasional, halting suggestions. I want to say I was Atlas hoping to trick Hercules into holding up the heavens for me, but that metaphor’s probably too grand. So let’s go with this one: I was hoping to pass the baton. Or no, not even that--by then I was mutely, merely wondering when someone would finally notice that, somewhere back around the curve, I’d mislaid the baton in a swamp full of alligators.

Henry remembers his epiphany, the moment at the end of that 2002 Child Study Team meeting, when Hannah’s aide Danene pulled him over to a quiet corner of the room and said simply, “Henry, it’s time for you to step up to the plate.”

Leave it to a sports metaphor to bring a young man to his senses. It’s all in the notebooks, as, in the months after that, presto, Henry appears on the scene again and again. He rises up at the same time I’m sinking, and for the same drab reason: he has no other choice. Oh, but wait, you could say—of course he had a choice. He could have left you for Lily (or the other one). He could have deserted all three of you—four, if you counted the dog, as Henry most certainly would have

done. Some men do that--they up and leave. I don't know how they do it, but they do. They announce themselves "finished," declare themselves—conveniently—too weak to go on.

So yes, theoretically, Henry could have chosen to bow out. But to make such a choice, he'd first have had to fling the best parts of himself off a cliff. Push had come to shove had come to havoc. His choice was all or nothing now, and he chose...well, okay, he chose "most," but I'm hardly complaining.

“The soul should always stand ajar”

Henry took over the weeknights. Sunday through Thursday, at a quarter to nine, he would moan at the clock, then drag himself down there, ten blocks to Hannah’s house. He hated it, but he did it anyway, and I let him do it, because I had to. I still dreaded weekends—those two nights when it would be my turn to stay with Hannah. And maybe that’s crazy, because Hannah wasn’t always unhappy, and sometimes we had lovely times together. But of course the deepest stress, for both Henry and me, stemmed purely from the never-knowing. We were, all of us, forever bracing ourselves for surprise attacks. Even the caregivers, despite their grail-like quest for patterns of cause and effect, couldn’t help, every day, but describe Hannah’s outbursts as “unpredictable,” “out of the blue,” “for no reason,” “out of nowhere.” “Hannah was in a good mood, then a bad mood and hand-bending, then a good mood, then bad.”

Henry washed, fed and dressed Hannah for school each morning. True, he dressed her with the same attention to fashion and grace he put into dressing himself—that is, none at all. They were two scarecrows, father and daughter. Neither could care less whether their pants were stained or their socks matched. Henry’s comb took only cursory swipes at the knots in Hannah’s hair. But he made sure she took her medicines. He learned how and when to change her maxi-pads when she had her period. (Once, sweetly clueless, he sent a box of tampons, instead of maxi-pads, to school with Hannah. Seeing the box, Hannah’s teachers looked at each other. Then Danene said, simply, “He’s got to be kidding.”)

Moreover, as Henry took on more responsibility, he shielded me from the full brunt of that dreaded inevitability: the caregivers’ judgment. For they couldn’t help it, you know—couldn’t help but study and judge us, especially as they came to see how much more “professional” than ours was their work with Hannah.

Sunday, September 13, 2003: *I got here at noon and Hannah hadn’t been given her meds yet because Nancy had overslept.*

September 18, 2003: *We will have someone come up at 7:00 AM on weekends to give Hannah her morning meds.*

While once they trusted me to know all manner of deeply unknowable things, I soon lose even the veneer of authority:

September 25, 2003: *Hannah attacked us several times. We called Nancy and Melissa 30 times and finally got through to Nancy who came down and called the doctor. Hannah was crying really hard and told Sarah and Melissa that her head hurt and signed "medicine." We gave her ibuprofen. She then became happy and was playful again. Melissa and Nancy left, and things were okay for about an hour, then Hannah lay down on the couch and started crying (with tears) really loud for about an hour. Nancy called and told Sarah and I to give Hannah more meds (pain), so Sarah called Dr. Sheppard to make sure. DR. SAID NO MORE MEDS!*

November 27, 2003: *Please also remember that Hannah is out of sorts this week because there was no school on Tuesday, and no school today or tomorrow. This means her whole schedule is off, and her parents have provided extra care. Hannah will probably be resistant to the pictures and other forms of structure because of this.*

June 5, 2004: *I was confused on her meds. Henry told me to do one thing and Nancy told me to do another. When I asked Melissa, she said as staff we need to follow the directions on the bottle. If we don't, we can get fired.*

Occasionally our Family Outreach caseworker writes to me directly. In vain she tries to teach me basic mothering skills:

Hannah typically wears a nightshirt [in the evenings], and she doesn't exactly sit like a lady. She should probably wear shorts or pajama pants. This protects Hannah and others from exposure to private areas. (It wouldn't be safe for children to see Hannah's underpants if she were outside in her nightshirt.) It is important to treat Hannah in an age-appropriate manner as much as possible, and also treat her as you would treat any other child her age. (If you would address this issue with Becky, address it with Hannah.)

But mostly they write to each other.

May 28, 2004: *Today at 10:10 she rolled her ankle again. Her face registered a lot of pain. We took her to the nurse, and she wrapped it and put on an ice pack. We called mom and left a message because she was not home. Maybe Hannah should get some high-top shoes.*

May 29, 2004: *I like the idea of high top tennis shoes for Hannah because her ankles are so weak.*

June 7, 2004: *Who do we need to talk to about getting Hannah some high-top shoes?*

Hannah's caregivers were grateful, at least, for small favors: "Melissa has talked with Nancy. We will have Christmas Eve and Christmas Day off!" But they grew more and more concerned by our absences and laxities—especially mine, I suppose. (Oh, to be a dad, the bitter mother muses, and garner glory just by showing up.) It's not that they thought we were *awful* parents. Any caregiver who'd once stayed overnight with Hannah was especially aware of how tough things could get. Instead, they saw us as we were—burnt out, inefficient, reluctant, scared. They began to express their concerns to Melissa, our latest caseworker. Melissa then sat Henry and me down for a long, private talk in which she admonished us to "get more involved." Henry remembers that talk vividly. He recalls Melissa's lecture as mortifying, humiliating, unfair. Meanwhile, except for its setting (shabby restaurant, corner booth), I myself hardly remember the scene at all, and would just as soon leave it that way.

By then I was, I thought, fairly numb to other people's disapproval. From a letter to a friend, July 9, 2002:

I took Hannah to a gynecologist, who'd never met her before. I was there to get Hannah a prescription for birth control pills. So I asked about it, and the doc looked Hannah over. I asked about dosages and side effects, etc., and the doctor answered my questions politely, but tersely. It was strange—as we talked she just kept staring at me with what I came to realize was contempt, thinly veiled. (I waited for her to press the secret, under-the-table button that would alert the police.) It took me another minute to realize that the doctor didn't understand that I wanted Hannah on birth control simply because (I'm told) it might stabilize her moods. No, apparently she'd thought I was just trying to make Hannah more pimp-able.

The fact was, I didn't need to look to others for disapproval. I had my own clever ways of finding it in myself. Go ahead—see if you can do it too. Pretend you're me. Go through the notebooks. Determine why, in the midst of such varied hardships, you find yourself most thoroughly crushed by this short, cheerful entry from June, 2005: "Mom came down today and

Hannah was so happy!!!”

“I sing to use the waiting”

But enough about me and my fathomless guilt.

To those who may be new to the business of maternal regret: you’ll have to give it up, I think, eventually—if only to calm the gentle friends telling you that no, no, you did the best you could, no one could have seen this coming, you were a great mother. It won’t be an easy surrender. In the first place, forget “great.” Try saying just this, right out loud: “I’m a good mother.” Never mind that you stumble, that you want to change the word “good” to “adequate,” or “not too bad,” or “better than my own mom, anyway.” That you itch to slip in at least a “maybe” or a “sometimes.” Dilute the statement as your shame requires—but only in your mind, and no longer aloud. You’re trying to soothe people, after all.

Nonetheless, you really will let it go, eventually. I don’t mean the guilt, necessarily. No, for all you know, the guilt will always ebb and flow, in accordance with lunar whim. You’ll get used to it. But what you will surrender, eventually, is the notion that your guilt makes you exceptional. You’ll discover, in fact, that it reveals you merely as a member of a beautiful, fallible, self-lacerating tribe. After all, when in your life have you met *any* woman willing to admit she’s a good mother?

I keep having to remember that, when you come right down to it, I’m pretty much beside the point here. I was who I was, did what I did, and remembered it all slantwise. I’m a feeble, flagging witness to my daughter’s story. It’s Hannah, of course, who’s the heart, and the hero. She’d have outlasted all of us, given a chance.

Along with her, I praise her guardians, at school and at home. I take comfort, even now, in their collective stewardship:

June 24, 2003: *Hannah was excellent tonight. She was happy and fun. She got her therapeutic ball today. It is allowed to be out for one hour a day only! She breaks them easy. Let’s hold on to this one so she can play on it from 5 PM to 6 PM every night.*

May 30, 2004: *When I got here, Hannah had been up all night, and boy did it show! She made quite a mess out of the house. She is still awake but in a very good mood. I had a ton of dishes to do this morning, and with Val gone, we’ll have to keep up on laundry and getting garbage out etc. We’re such a good team I don’t think we’ll have a problem!*

September 24, 2003: *We have a new documentations system to monitor Hannah's day. There is another big white binder with sheets for every shift to fill out. We'll use these forms to document Hannah's behaviors/medical and PMS issues, menstrual cycle and what/when she eats. Anything and everything that happens is worth writing down.*

June 12, 2004: *Hannah went an entire week without a major aggression! WOW—this team is doing it right! I think a consistent schedule, maybe that nighttime snack, and getting to the park are doing a lot of good too. I think it is sooo neat that Hannah walked to the Dairy Queen! Way cool!*

August 1, 2003: *We need to document Hannah's meals on the weekly menu in the grocery list section of Hannah's log book. We really need to be sure she is getting balanced meals.*

February 28, 2004: *Here's the new schedule. Remember, it doesn't mean that matching [a DTT program] has to happen at exactly 7:00 PM. Trust yourselves to know when Hannah's ready and where she's at moodwise. The schedule is not set in stone, it's a guide to help us get Hannah to a good place. We are all here to improve the quality of Hannah's life, and together we're doing a really great job.*

Sometimes, during her last couple of summers, I might be driving home from errands and catch a glimpse of Hannah, down at the cloverleaf where Harrison Avenue connects with I-90. As part of the summer special ed curriculum, she worked there, side by side with her beloved shadow, Sue. Her class commandeered the vast island meadow, mowing the grass and stuffing the clippings into black garbage bags. The brawniest teacher did the mowing; the boys in the class were the primary rakers. Sue stooped to gather grass like a gleaner in a Millet painting. Hannah, meanwhile, played the crucial role of the girl who held the garbage bag.

Even more often, Hannah played the girl who sat on the picnic blanket, swigging from her water bottle. Or else holding reasonably still as Sue swathed her in sunscreen or brought out her lunch bag. Once, trapped at a red light maybe fifty yards away, I watched from my car as Hannah pounded her head, again and again, against the newly mown hillside. Along with the brawny teacher, Sue was already rushing to restrain her. I watched the scene blankly, as if it were

somehow a metaphor, a simulation. After ten or twenty seconds, when the light changed at last, I lifted my foot from the brake, let out my breath, and drove on past.

I wrote a song for Hannah once, when she was fourteen, and I sang it to her sometimes—but then, I was always singing. Once, though, I sang it to her before an audience, in Butte’s Orphan Girl Theater. We sat center-stage, in cozy easy chairs half-facing each other, and Hannah was happy to be there, affable and curious despite the bright lights, the darkened hall, the hubbub backstage, the long minutes waiting in the wings for our cue. At each of three performances, she swayed in her chair, letting out her own occasional “shabeesh-shabeesh” or “bah-dah-bee.” She peered out at the dark audience, shielding her eyes with one hand, a drunken sailor on watch for pirates. Now and then, of course, she flashed me one of her trademark wild-eyed grins and made a playful swipe for my guitar. Luckily, for a clumsy person, I have very good reflexes, and was able to swoop in and out of her reach without missing a chord.

We were part of the Same Difference Inclusive Theater Company (SDITC), an acting troupe of local kids and grown-ups “with and without disabilities.” Founded by Melissa Santora—the dynamo of creativity, energy, and compassion who would eventually become Hannah’s Family Outreach case manager—SDITC was a fabulous, lunatical enterprise. Becky, Henry, and I each took part in dozens of projects over the years—plays and musicals, Christmas pageants, revues and skits, not to mention all the bake sales, raffles, parade floats, awards dinners, and—egad!—that ridiculous “festival of fright” we put on every Halloween, in an empty dress store at the mall, where I read fortunes, maybe, and Henry enunciated bingo numbers through vampire teeth, and Becky made evil bwahaha noises while thrusting out a skeleton hand from beneath a dressing room door. (You knew people wanted their money back afterwards, but only the most hardened among them dared demand it of the cute little deaf boy in charge of the cash box.)

The occasion for which I sang to Hannah onstage was the debut of what would soon become the group’s eponymous, cornerstone play, “Same Difference.” It was a collection of short scenes and songs, each centered on a different aspect of disability. Hannah and I opened the second act.

The song was called “For Only You.” I include the lyrics here, I suppose, as one last figment of a long-gone dream:

1. On my knees I peered at you through a crooked blind.

*Only matching bracelets on to tell them you were mine.
I remember later on—the hospital gone dark
In a late-night lightning storm—I held you heart to heart, And
promised you....*

[Chorus:]

That I would live my life for only you.

My every day and night for only you.

My dark and then my bright.

1. My sorrow, my delight.

2. My blindness and my sight.

3. My comfort and my fright.

2. Rolling 'round and 'round the bed on flannel afternoons,

As everyday our private sun would melt me into you—

Three years went by in just this way, and how was I to know

The world demanded more of us, and yearned to tell us so?

And all those days, I promised you.... [chorus]

And then came the doctors, the teachers, the therapists.

Neurologists, psychologists, pathologists, apologists,

Pediatricians, lab technicians. Awkward brother, rosary-saying mother.

And they all meant well, but none of them could tell me what to do. And

when they looked at you, their stares were blank then, too.

3. But some had papers, some had pills, and so they all made plans.

They gathered in a chalk-filled room, drew charts and diagrams.

They developed a program with specific objectives.

They established clear outcomes to extinguish behaviors.

And late at night, I held you tight, and promised you.... [chorus]

4. We chronicled, those secret nights, the pathway of the moon,

Till someone thought of trazodone to keep you sleeping through.

And bit by bit you slipped away, and bit by bit I died,

While wondering, were you ever here, or always locked inside?

And still I promised you...

Days. Years. I will not deign to tell

Just how it was, and all that passed, and how it felt.

5. But look at you, my darling girl—nearly a woman now.

In spite of all we've put you through, you'll grow up anyhow.

But we can still roll 'round the bed, the way we used to do.

And if you'll look outside, my love, I'll still show you the moon,

And I'll promise you

That I will live my life...

And you will live your life, and only you Can

know your own delight. My only you.

We're facing the day now, we're making our way now— Our

dark and our bright.

Our blindness and our sight. Our

comfort and our fright.

Our greatest sorrow...and our greatest delight.

“Ample Make this Bed”

Memories of Hannah’s seventeenth birthday party, July 18, 2005: We drove to her house—Henry, me, twelve-year-old Becky, and Becky’s best friend Kristin. Becky brought Hannah a little stuffed bear. Kristin’s gift was a helium balloon, but as we got into the car to go to the party, it came loose from her hand and blew away. I myself had bought Hannah a bright polyester windsock, with a butterfly theme and dangling rainbow streamers. When we arrived at Hannah’s house, I hung it up, straightaway, on her big front porch, in a spot she’d be able to see from her living room recliner: a small-time exuberance of color and motion that I hoped might divert her year-round, even throughout the drab, gray winter that would come soon enough.

Melissa brought the cake. Three or four other caregivers also attended, though I’m afraid I can’t remember which ones. There may also have been pizza and/or ice cream. Hannah was happy that day, but introspective, not very social.

Henry and I share the same iconic memory: Hannah sitting, paper plate on lap, gleefully devouring her slab of cake. Her head bends low over the plate, no doubt to narrow the gap between fork and mouth. Henry and I can picture this scene like a photograph. Our visions differ in only one respect: Henry sees Hannah on the living room couch, whereas I’ve placed her outside, in a folding chair on the front porch. So much for memory.

We must have hugged her—mustn’t we? We must have said goodbye. She paid us only slight attention, but that hardly mattered. On this fine afternoon in the third week of July, my daughter was happy.

Montana summers are temperate and lovely, and I can think of nowhere else I’d rather be, in summer, than here. Thus I always found it a little sad that, year after year, we spent so many summer days in Queens, New York, holing up in the Gonshak basement as if you can wait out humidity the way you do hurricanes. Every summer was the same. We sat on wooden chairs, reading the New York Times in its daily entirety. We watched beads of condensation mingle into rivulets that wandered down the sides of our aluminum water glasses. We silently pondered the question of who sweat more, Irwin or Henry, for both were very hairy people. (After coming downstairs, once, to find Avis using an electric razor to shear fur from Irwin’s back, I had trouble shaking the notion that I’d just glimpsed my own future.)

Our caregivers were in place, our support staff on call. We'd be away for a bit over two weeks this time. The day after flying to Queens, we drove Becky into Manhattan so she could board the chartered bus that would deliver her to a two-week "theater camp" in rural Pennsylvania.

Afterwards, and for the next several days, Henry and I had our usual pretty good time in New York. We went out with friends and family. We wandered around Manhattan. We ate at great restaurants, we sat in the park. We spent the hottest afternoons in the shelter of movie theaters, traipsing through this summer's list of "movies that'll never get to the mall." And if the Mets were in town, we probably took in a game.

Every other day or so, we called home, and were told things were going well. Of course there were "incidents," as people called them, but no more than usual. Meanwhile, Henry and I were getting along pretty well. It seems that, once we'd figured out I wasn't Superman, we'd had little choice but to become—of all improbable things—partners. Even our marriage counselor, with a kick and a blessing, had flung us at last from his oak-paneled nest. My twitches twitched on, and I surrendered to low-level attacks of anxiety and depression, but in New York I was usually pretty okay. After all, along with Becky and Henry, I wasn't merely "on vacation." On the contrary, my escapes were now routinely considered therapeutic necessities, and I took silly comfort merely in the drab little social-work word for it: "respite."

I spent the last few days of the trip in Valhalla with Ben. He was to me by then what he is today: confidant, friend, co-solver, big brother, occasional port in a storm. I'd lost my escapist fantasies by then. That is, his apparition and I no longer swapped romantic *bon mots* as, say, I uprooted hairballs from the bathtub drain. Instead, this summer, my days and nights with him were simple and fun.

I left Ben's house, that Friday morning, at around ten o'clock—my idea of an early start. Henry and I were set to drive six hours that day to meet Becky at theater camp. We'd watch her in a play that evening, stay overnight at a nearby hotel, drive back to Queens on Saturday, fly home to Butte on Sunday.

Gingerly—because I always imagined my father-in-law fretting behind the window blinds—I eased Irwin's car into the narrow Gonshak driveway. Humming songs I'd been singing full-throttle along the Saw Mill Parkway, and feeling "ordinary," which by now had become a direct

synonym for “good,” I entered the house. I may have announced myself with a hearty hello. Then I clomped down the echoey basement stairs.

Avis and Irwin sat there, in stiff chairs at the kitchen table. They looked up when I appeared, but said nothing. Henry sat off to the left, in the far, dim corner where they kept the telephone. He looked dazed. He couldn’t speak right away. He stared at the floor... Thus the scenario played itself out with typical surreality, I suppose, as if, to our dull astonishment, we were now merely characters in a ghastly melodrama.

Henry says I figured it out quickly. He says I saw the phrase he’d scrawled on a notepad by the phone—“Butte Coroner,” followed by a phone number. “That was when I knew,” he says I told him later. I don’t remember this at all. Neither can I quite make out the difference between what I remember and what I think *must* have happened: Henry had me sit down. He said he’d tried to get a hold of me at Ben’s. Hannah, he said. Hannah was dead.

No. “Hannah has died”—those were his words; I remember them only because later I thought how curious it was: that “has died” might serve, somehow, as a feeble euphemism for “is dead.” “Hannah has died”—as if this were just the latest of her activities, and, any minute now, she’d be doing something else entirely.

Our friends Butch and Gretchen had called Henry, maybe an hour earlier. Before the trip, I’d granted Gretchen power-of-attorney over Hannah during the days we’d be gone. Now, on this hard morning, to her credit and our relief, she remained unflappable. She took charge of events as they unfolded that day, managing the police, the paramedics, the funeral home.

When first she’d arrived, and begun tending to Hannah’s body, Gretchen’s years of nurse’s training had taken over. It was fortunate, she said later, in a nebulous comment that I will never ask her to clarify, that her profession had taught her “what death really looked like.” It was Hannah’s caregiver, Brandon, who had found Hannah that morning. He’d gone into her room as usual, at seven a.m., to wake her for school. Hannah’s body, cold and still, lay on the floor beside her bed. She had died hours earlier, they all guessed, eventually. Sometime between midnight and three or four a.m., they guessed.

No one will ever know how Hannah died. Not even the autopsy, performed at our ambivalent request, could solve that final riddle. The eventual consensus was that she must have had a

seizure, lost consciousness, and stopped breathing. Some people, later, getting “fact” and “hope” mixed up, assured us that her death had probably been “painless.”

And that made crazy sense to me, that we would never know for sure how Hannah died. The autopsy was just one more test that came back “negative.” As with a lifetime of metabolic screenings, genetic tests, MRIs, CAT Scans, EEGs—there were “no significant findings.” Thus we gaped, one final time, before the chasm of our ignorance. Our beloved enigma was lost to us for good, and no one—not a single one of us—would ever know just who she was.

"Tell all the truth but tell it slant"

I find myself *this* close to making the following joke: that, luckily, when you're inching your way up the on-ramp to the George Washington Bridge, nobody else in the million-car line finds it strange that you're howling in despair. But in fact I wasn't howling, not right then. That impulse wouldn't hit me till the next day, on the crowded airplane home—a milieu in which howling in despair is still, somehow, not an everyday event.

We drove to Pennsylvania to pick up Becky. That night she'd play Sally in the camp production of *You're a Good Man, Charlie Brown*. We decided to wait until after the play was over to tell her about Hannah. And the whole day was filled with decisions like that one. "What would a reasonable person do right now?" This implicit question guided us through the motions of the day. We filled the car with gas, we made sure to bring the map to Becky's camp. I'd already called the airline to change our flight home to tomorrow instead of Sunday. I drove the speed limit. At a certain point along the highway we stopped someplace to eat—White Castle, I remember. Only once before, in my provincial life, had I ever visited a White Castle. Now, those slippery gray mini-burgers seemed proper to the surreal occasion: the sort of synthetically manufactured fast food they'd serve on the moon.

We watched Becky's play—another surreal event, all these chipper little campers putting on their funny, fine show. I remember how excited she was, how during intermission she visited with us for only a few seconds—a good thing, under the circumstances—before running off to confer in effusive whispers with her fellow actors. I remember desperately wanting the play to end, because it was so hard to keep sitting there like some ordinary person watching an ordinary play on an ordinary evening. I remember, too, wanting the play *never* to end, because I knew that, in one impossible sentence, we'd soon be yanking Becky down from all this joy, down into a world I wish she didn't have to know about, much less inhabit.

But it's much better to let her tell it, in an essay she wrote in high school, a few years later:

To this day I have negative associations with Krispy Kreme doughnuts and the musical You're a Good Man, Charlie Brown. Three summers ago, I went to a performing arts camp in Pennsylvania. On the last night of every session, we had a big final production, and this year it was You're a Good Man, Charlie Brown, and I was playing Sally. I was

really excited, because my parents were coming to see it. We spent all day rehearsing and then getting into hair and make-up, and then it was time for the performance. The play went fine. My parents were in the audience, just like I'd expected, and greeted me with a hug afterward and told me what a good job I'd done just like I'd thought they would, but then my parents told me they wanted to talk in private, and that should have clued me in.

We separated from the crowd of proud parents and energetic, chattering campers who in a few minutes would be off to the ice cream social. We sat down on a bench, far enough away that I couldn't hear the happy voices, except for my own. I was still jabbering away, asking them what their favorite part of the play was, regretting that I'd forgotten the words to my solo, and ironically, I was really happy right then. It had been a great summer. I didn't notice the solemn expressions on my parents' faces, while I was so exuberant. I had no idea what they were about to tell me. Nothing tragic had ever happened to me.

"Sweetie, there's something we need to tell you, and it's very difficult for us," my mom said. Suddenly, my good mood vanished, and my mind started racing, wondering what they were going to tell me. I thought my dog must have died, because it was the worst thing I could possibly imagine happening.

"Hannah has died," my dad choked out. I was in a haze. This couldn't be real. It must be a joke I wasn't getting. I smiled tentatively.

"It's not a joke," Mom told me gently. "She had a seizure in her sleep." If it wasn't a joke, it had to be a dream. I never needed to pinch myself to figure out if I was dreaming. I could always tell, because my senses were so much sharper in real life than in my dreams. I tasted the air and felt the texture of my jeans. If this was a dream, it was the most realistic dream I'd ever had. Once I realized it wasn't a joke or a dream, I knew I had to cry, and for a second I wasn't sure if the tears would come. I was worried that they wouldn't, and I'd be forever known as the callous girl who didn't cry over her own sister's death. I needn't have worried, because in a second I was wailing, and once I

started I couldn't stop. I cried on alternately my dad's shoulder and my mom's. They must have been in a miserable state too, but they tried to be strong for me.

Mom thought I should stay with them that night, and of course she was right. I couldn't go to the ice cream social and pretend to be all right when the world had just collapsed. Then again, I didn't want to leave without saying goodbye to the friends I'd made. I hadn't even gotten their e-mail addresses, so we could keep in touch. That was the main purpose of the ice cream social. We decided that I'd go back to their hotel that night, and tomorrow morning I'd come back to camp for the final breakfast and say goodbye to my friends. We had to talk to the Dean of Campers, who didn't like the idea of me leaving and then coming back, but when something horrible has just happened to you, people can't help but give you what you want. She drove us to the main office in a golf cart, and I sat in the back and sobbed some more.

There was a Krispy Kreme next door to my parents' hotel, and I asked my mom if we could get some doughnuts. She thought that was very appropriate and that when you're in mourning you could eat whatever you wanted and not feel guilty about it. I had two doughnuts and then felt sick.

I lay on the hotel bed, finding pictures in the texture of the ceiling, still in a daze, trying in vain to process what had happened. My seventeen-year-old sister, who had been perfectly alive when I'd left for camp, was dead. We hadn't been close. I didn't mention before that Hannah had had very severe autism. When I was little I was afraid of her. She would have violent tantrums sometimes, and I would flee to the basement. She got better once she'd gotten past the worst part of puberty, and I stopped being afraid of her, but I still didn't know how to interact with her. I couldn't talk to her. So even though we were sisters, in many ways we were like strangers.

It's been three years, and I guess you could say I've gotten over Hannah, in the sense that I don't cry when I think of her and it's only when I relive that night that the haze surrounds me once again, and I tremble from the pit of my stomach to the tips of my fingers, but only for a second. My sister's life and death molded me and made me who I am. Her life made me patient, calm, and strong, but her death made me serious and woke

me up to the fact that people die and someday I'll die, too. I honestly don't know if Hannah loved me or even knew who I was, but I know I will always love her, and I will never forget her.

“To learn the transport by the pain”

A few small, good things:

I can never remember the date she died. I surely knew it once, or twice, and could look it up again if I wanted to. My sister knows: on what must have been its first anniversary, she phoned me, asked, “How ya feelin’, darlin’?” and offered other sympathies, and it took me forever to figure out just why. Even so, I quickly forgot the date again. It’s easier this way. The fact that there’s no “anniversary”—only some, no doubt quite particular date in early August—disseminates the memory, scatters its ashes over a wider area, forbids it to crystallize into a single, cold, diamond-hard event.

Another lucky thing: we weren’t there. A left-handed blessing, to be sure, but you know me by now: between guilt and relief, I always choose both. The guilt softens when I think of Brandon, whose gentleness and expertise confirms for me that Hannah would have died no matter who’d been watching her that night. The relief grows when I ask myself, but what if *I* had been the one? I, who slept, you’ll recall, with my bedroom door locked and my noise machine turned up high. Even now, I get just a wee bit hysterical, imagining that dreadful scenario.

But it wouldn’t have been me. Hannah died on an early Friday—on what would have been Henry’s watch. So I imagine that prospect. I don’t think I’d have blamed him, exactly. (I’d have blamed myself for not having been there instead, and for buying the stupid noise machine, and keeping my door closed. And why didn’t I install a baby monitor in her room? Why did I believe the doctor who insisted her seizures weren’t “serious” instead of the caregivers who insisted they were?) It wouldn’t have been fair to blame Henry—I’d have known that immediately. But our marriage was still so fragile then—we were both only just now recovering from our lifelong habit of blaming Henry for *everything*, after all. So, who knows—however unfair, I might have harbored some niggling, niggardly qualm. Meanwhile, Henry would have blamed himself for the rest of his life without ever once admitting it, even to himself.

We weren’t there, nor do I know the details, quite, of all that happened during the hours after Brandon found Hannah. Just as I’ve never asked Gretchen to clarify “what death really looked like,” I’ve never asked Brandon for that morning’s details. He must have told us everything, of course, but I recall it only vaguely. No, what I found, when we flew into Butte the next day and

drove straight to Hannah's house, was her silent, empty bedroom, tidily arranged. Gretchen had replaced Hannah's bedding with a pretty, handmade quilt. (I never knew what became of Hannah's own sheets and blanket.) Gretchen had also picked a small bouquet of flowers from her garden, tied them together with a green ribbon, and placed them on Hannah's pillow.

When people make such quiet, graceful gestures, I wonder if they know the good they do. Later on: all the cards, flowers, charitable donations. The day Deacon Dan, from Becky's church, brought over a basket of ham, bread, cheese, apples. Peace lilies from the owner of the pizza place where I sometimes sang for tips on Friday nights. Blueberries from a friend's back yard. Every little gesture was indispensable. Moreover, their mere accumulation astounded us. Even just the sympathy cards—a barrage of them, many (more prized, somehow, because less likely) from people we didn't know well: Becky's friends' parents, Henry's colleagues, neighbors we'd never met. To this day, I've saved every one of them—like artifacts, like proof.

The mortuary people did their jobs well. Moreover, they remained as close to invisible as they could. We “viewed” Hannah's body in a soundless, chapel-like room. Though scheduled for cremation, she'd been placed in what I guess was a sort of “loaner” coffin. She looked asleep. She looked real. She looked—I guess—“at peace.” Even when you touched her cheek and wept at its coldness, even when you finally knew, for sure, that her spirit had long since flown, leaving only this sweet mute mannequin behind—still you fought an urge to grab hold of her shoulders, to shake her back, somehow, to life.

They'd performed the autopsy that morning, but they'd arranged Hannah's body so you couldn't see the wounds. How Henry and I had vacillated over that procedure. We must have known, bone-deep, that the exam wouldn't “find anything.” Yet somehow we'd needed to go ahead with it—to ask just one more unanswerable question, conduct just one final worthless experiment. Not even death, it seemed, could keep Hannah safe from our quackery.

We held a memorial gathering in the big front yard of Hannah's house. I say that “we” held it, and think it was probably my own idea, but I don't remember doing a thing to put it together. Henry announced its date and time in Hannah's obituary, which appeared in Monday's newspaper. The memorial came together in a flurry on the following afternoon. I sat on

Hannah's front steps as a big truck pulled up and a crew of high school boys leapt off the back. I watched them unload long cafeteria tables and folding chairs, which they set up in neat rows on the lawn. I don't know who asked them to do this. Likewise, someone brought plastic tablecloths and big yellow candles to serve as centerpieces. Someone else set up a mike stand and speakers. My dear friend Mary brought a portable electric piano because I wanted her to play Hannah's favorite songs, especially "Moon Shadow." Many people brought napkins, plates, food and drink.

All told, about a hundred people attended the gathering. Caregivers, teachers, classmates past and present, Hannah's speech therapist, Hannah's bus driver. A doctor I knew only from our many emergency room visits, as well as Hannah's dentist and her longtime pediatrician. Friends, colleagues, neighbors, the entire Same Difference troupe. Deacon Dan offered a prayer. Mary played "Moon Shadow." People stood in line to console us. They stood in line to fill their plates with baked beans, coleslaw, macaroni salad. They stood in line, eventually, before the microphone stand, and, one by one, told Hannah stories.

Hannah's school aides talked about times Hannah would chase them around the classroom table, lunging to get at them—how she'd go one way so they'd go the other, how nimble they'd all learned to be. And the crazy thing was the way, as they told such stories, they were laughing, laughing, and in the audience Hannah's other caregivers were laughing too, and there was such love in their laughter that I glanced around at other people in the crowd, who likely didn't know Hannah the way the rest of us did, and wondered what *they* must be thinking. "Oh, she got me good that day," Sue, Hannah's fearless shadow, chortled in recollection. How was it possible? I sometimes think. Just how magical *was* my daughter, that she could inspire so many of us to regard even our scars as badges of honor?

The story I remember most vividly, and the one that finally made me cry, came from Hannah's classmate, a delightful, autistic boy named Chris. His flat, gravelly voice punctuated by giggles, Chris announced his favorite Hannah memory: her sudden, urgent dashes to the bathroom--most especially her habit of pulling down her pants long before she got there. He noted other endearments as well: the times she rocked so hard he thought her recliner would fly into space, the way you had to hold your lunch tray high or she'd steal your food, the day he thought he might have heard her say his name.

Five of my brothers and sisters came out to Butte for a few days. To my muddled mind, their visit was a surreal intermission from grief. We drank and ate and played games, mostly. We pieced together a giant jigsaw puzzle on the kitchen table. One evening, a gentle neighbor who assumed our family was ‘sitting Shiva’—in Judaism, a formal time of mourning—brought over a pan of kugel (a sort of noodle pudding), only to find the gang of us laughing, drinking, playing poker.

One night soon after Hannah died, a group of high schoolers—five or six of them, scruffy, slouchy, twitching with unease—came to the door to tell us how sorry they were to learn the news. She’d been their friend, one of the boys told us. Every day in the cafeteria, they’d “watched out for her,” rushing to defend her against any kid who “said something mean.” As tonight they stood hunched in my living room, shifting their weight from foot to foot, I felt a gap and a bond, at once, between us. I asked them to sit down; they demurred. I wanted to hug them, but got the feeling they’d find it awkward. I wanted, at least, to *give* them something, I didn’t know what. In the end I handed each kid a copy of Hannah’s newspaper obituary. They took and held these clippings gently, as if they might be fragile or, maybe, sacred. One of them—who, beneath her army surplus jacket and ragged hair, I only now realized was a girl—began to cry softly. Meanwhile, I could do no more than thank them all, over and over, and to marvel again, in my helpless daze, that my little girl had had such brave and beautiful friends.

“This world is not conclusion”

From a letter to Hannah, March 26, 2016:

I opened the yellow basket today—that wicker thing, on the top shelf, that you were always so bent on pulling down, but never did. (I know this because it still exists.) It’s been years since I opened it. Not that I’m scared of it, exactly. I just wasn’t quite ready to take inventory.

My nun doll’s in there, from when I was six; someday I plan to reattach her arms and legs. (So you see, honeybunny? Mommy used to break her toys too!) I also found the other things: my “basal body temperature and mucus” charts, hazy ultrasound images. The paper surgical mask and booties Dad wore in the delivery room. Our twin wristband IDs—both pink, yours tinier. The knitted cap and bib the hospital supplied when they finally let the two of us go home. Assorted pamphlets: “Car Seat Recommendations.” “Emergency Choking Aid for Infants.” “Helping your baby sleep through the night.” (Ha!) Congratulatory cards and letters. A list of a dozen people I probably still owe thank you notes to. A placard from the hospital bassinet, identifying you for the first time as Hannah Gonshak, with your first primitive signature—two wrinkled footprints, tiny but bold, inked in black below.

The thing that almost “got me good,” as Sue would say, was the lovely lock of your hair, but that’s only because I’d actually forgotten it. It lay coiled, tied together with a yellow band, in a fusty plastic bag at the bottom of the basket. It must be a souvenir from a haircut I gave you when you were two years old--no younger, since it’s four inches long and as thick as my thumb. It’s a tidy sheaf, one end blunt and uniform from the scissor-cut; the other end wispy, of various lengths, curling up at the ends like it always did in those days. It shivers with life, still; it looks freshly clipped. It delights, even now, in its shiny blond-brownness. As I stroke it, smell it, hold it in my hand like a beautiful dead bird, it’s a good thing your dad’s not around, honey. He thinks I’m already so terribly morbid these days.

I'm sure you can tell: this letter is different from my usual scribbles to you. For one thing, you'll notice, there's a lot more punctuation. Also, I'm not weeping uncontrollably. (Ha.)

Another thing that makes this letter special—or, anyway, different—is that I'd like to end the book with it. A plausible idea, you think? I hope so. Now if I could just figure out what to write.

Maybe this last chapter ought to be yours, sweetie. So, all right, what would you like me to say? Just kidding. I know you never fall for questions like that, questions that require “opinions.” Once you die, after all, the very least the afterlife can do for you is to free you from the bother of having opinions. One cool thing about you, Hannah love, is that you never had opinions in the first place. Not about trivial things, at least. You did prefer ice cream to rice cakes, but that's just common sense.

One thing I just thought of today: I wonder if I've spent too much time obsessing over how “mysterious” you always were. I mean, yes, of course you were mysterious, but maybe only in the most usual, trivial sense. Meanwhile, merely to look at you, to spend time with you, was to know you more intimately, more primally (that word again) than I'm likely ever to know anyone else.

So there's that. I did know you, in many ways, sweetheart. A lot of people knew you—we just didn't know quite what, or how, we knew. It's amazing, Hannah: your effect on people. What drew them in every time—it wasn't pity. No, you seduced us instead with what I want to call—don't laugh—a rare charisma. Do you get what I mean? You startled us all, and kept us startled for years, with the stark purity of your innocence. No matter the moment, you were guileless, sinless, unsulliable—as fully exempt from corruption as the Virgin Mary. No wonder we loved you so dearly. No wonder we took pride in our scars. No wonder we couldn't help but become, around you, like those ancient tribesmen who'd have regarded you as a spirit guide, a shaman, a gift.

When people ask me to describe you, love, I yield to the ineffable. “She was really something,” is all I tend to say. (I don't suppose it's very helpful.) Nowadays, though—and it may not be important at all—I've changed the sentence. “She was the real thing,”

I've been telling people lately. It's how Dad and I talk when we talk about art. We always come down to that vague but basic question: is it "the real thing"? It's also the question I ask myself, about myself, all day. (And it's the reason I named my blog "isthisanything".)

Meanwhile, you, Hannah Banana—you were always the real, pure thing. It's what made you my best teacher. You taught me to bear the unbearable. To love without condition. To live in the here and now. You taught me the trick of not-minding. And you taught me nonmaterialism: e.g., the relief inherent in owning a carpet so grubby and stained that adding a layer of finger-paint would surely do less harm than good.

Which reminds me: how I miss you, Hannah. How I wish you were here—though my wish gets mixed up when I think of all the horrors you went through. I want to ask you, are you happy now? It's a dumb question—unanswerable. I talk to you like you're really here, but I can ask you only those questions whose answers I already know. You reply mutely—my laughing Buddha who knows that most of what I want to know remains, quite simply, none of my business.

I fall into a trance with you sometimes, the way we'd fall together when we two were both such babies, the way we stared at each other as we nursed all day and night. Dreamy-eyed, awestruck, milk-drenched. Did you know, even then, that it was all a game? I thought you did, sometimes, and all the time you were growing up, I kept suspecting—out of the corner of my eye, I guess—that you saw life more clearly than I ever would, that you were older and smarter than all of us, somehow. I even got the feeling, sometimes, that, to the extent you went along with "civilization," you did so just to humor us, when all the while you knew quite well that eating with utensils, wearing clothes, using toilets, were nothing more than little, empty rituals.

If only you'd been happy, honey. Happy—that word over-haunts me. But when you were here, I told myself—once you dragged me to a height where I could see the puniness of almost everything else—that if only you were happy, nothing else would matter. Such a clear-cut wish to make, I thought, so clearly not like one of those backfiring wishes from the Arabian Nights. It turns out, even so, to be impossible: I can't split you into parts,

discarding everything but bliss. For all I know, your miseries were—no, I still can't say it. I can't say they might have been "necessary" or "intrinsic" or "inextricable." That's a peak I've yet to reach, I guess, though I glimpse it now and then.

Apropos of nothing, love: I'm sorry we all were such blundering snoops. We always had to ask and ask: what you wanted, where your pain was, why you rampaged, who you were. We graphed your every move and stillness, but all we found were apophenic patterns. That time Jeannie spilled a full pitcher of juice, and you said to her, quite plainly, "What a mess!"—oh, how you loved to tease us with such evanescent miracles. You had God's sense of humor, I'm coming to think. Every now and then, just for a laugh, you'd prank us with your own version of the face on Mars, or Jesus in a piece of toast.

In retrospect, I wonder: maybe none of us was meant to know the "reason." Maybe, in fact, there wasn't one. Was that the koan's answer all along, love? That life is purely what it is, and "why" is a silly question? At any rate, darling, you were the cagiest of gurus. You loved and blessed us, but you never stooped to soothe us with a single forthright answer.

I used to mind the never knowing. But nowadays, I kind of smile to think of it. This book—did I ever really think I'd find answers here? I surely don't think that way now. So it's fitting, at least, and it floods me with strange relief, to end things just like this, with one last salute and surrender. "She was the real thing"—from here on out, that's all I'll need to say.

Oh, but Hannah, even if I could know everything, right now—if somehow we met up again, and had a bright eternity for questions and answers—even then, I wouldn't need to know any more about you than I already know. I've been thinking about it a lot, in fact—this sweet little eternity we might somehow, someday spend together. If it happens, how about we just skip the questions, sweetie? In fact, unless you want to, how about we hardly speak at all?

If you're willing, Hannah love, what I'd like to do first is just rock you in my arms again, and listen to you babble. Then maybe we could build a blanket fort. We could have ice

cream sundaes for breakfast. We could sit at God's big desk, rolling out Play-doh spirals, making chains from paperclips. We could roll around in God's bed. We could go to God's park, if we felt like it, or else just stay home and watch videos. Maybe we could find a swimming pool to jump in, or a big pile of leaves.

Maybe, darling—maybe?—we could sing.

Here's to that forever, darling girl. I love you with all my heart.

Mom