Hannah has a crush hold on Barney’s leg. Here it is, her second birthday party, and my daughter stands cement footed, clutching our star guest, a purple dinosaur.

My son, Charlie, has just turned four, so this is his party too, and we’ve invited his friends from preschool. Everywhere kids bound through the house, yelling, laughing, taking each other out with couch cushions and throw pillows. Restoring order only when it’s really necessary, the adults chat and buzz about; everyone is comfortable and happy. Everyone except Hannah.

In the midst of all the bustle, all the festivity, she seems seized. Locked down. Like a kid staying put on home base or stuck in a game of freeze tag. But Hannah isn’t playing a game. She’s not playing at all, not with the other kids, not with her new toys, not even with the TV and the VCR.
And not with Barney either. She simply clings to him as if her life depends on it.

When she finally lets loose, Hannah turns her unshakable embrace on me.

It occurs to me that maybe she's experiencing sensory overload. After all, pretty much everything in the world is “new” for a two-year-old. Maybe the party is too much, too fast.

Yet Hannah had played with other children who came to our house when we lived in Massachusetts. What is this?

Then it hits me: no kids. Since we moved into our new home in Northport, Hannah's big brother and I have been her only playmates. In our new neighborhood, she has no friends.

Yes, that's it, that's the problem. I guess I can't justify keeping her all to myself anymore. Hannah obviously needs more exposure, more social interaction with children her own age.

She'll start preschool early, I decide. It isn't my preference, but I want what's best for my little girl. And, just maybe, it's time I loosen my grip a little too.
A few weeks after the party, Hannah goes in for her two-year checkup, where her pediatrician delivers the “all clear.” I take the good news and run with it. But over the next weeks, concerns keep cropping up. Han still doesn’t speak much; in fact, she seems to speak less. She shows trouble understanding me and isn’t meeting the milestone accomplishments I see other kids making. She doesn’t use her hands, except to clap a lot. And she isn’t at all interested in mimicking what I do. I thought this was supposed to be the “me too” age. Instead, it seems as if Hannah couldn’t care less about me, about anybody.

Every parent receives the same cautionary advice: don’t compare your children to others, because every child is different. But Han’s not just different from her brother or other kids. The most glaring difference, Charlie and I agree, exists between the Han we know now and the Han of just five or six months ago. Wasn’t it our little Hannah who had set the table with her play dishes for Christmas dinner? It was. So who is this new child,
so disinterested and apart from it all? Why is she so quiet? And why are we always finding her in front of the TV, eyes fixed on a Barney video, which she now prefers watching in fast-forward or rewind?

Something is wrong.

Not just sort of wrong, but really wrong. On Hannah’s first day of preschool, I feel more than the typical parental apprehension, more than that pang of grief that comes with “liftoff.” This is nothing like what I experienced with Charlie. I’m a nervous wreck.

I’m a little anxious when I drop her off. She’s not even two-and-a-half, after all. Until this point, she’d been with me practically every minute of every day, so of course I’m anxious. And as the day moves along, I imagine what she is doing moment to moment. Then the uneasiness takes over. Mothers will talk of a sensation, an intuition, an inner voice that tells them their child is in trouble. Hannah and I had always shared a tight bond, and I’d heard that voice before. There is no doubt in my mind that I am hearing it now.
I let a few more minutes pass; no call from the school. Hannah's session wouldn't end until 1 p.m., but by noon I am in the car. Hannah has been away only a few hours, but I can hardly stand it anymore. A warning bell goes off inside me; I have to get my girl.

I’m the first mom to arrive at school—a good twenty minutes early—and I discover that Hannah's teachers have been waiting for me.

As I approach them, I see their hands lying like a lace shawl on my daughter's shoulders, they steer her toward the door and bring her out to me.

"Is Hannah deaf?" one of the teachers asks pointedly.

I’m stunned silent for a moment. Then, as if someone has flipped a switch, I’m upset, angry. Do they really believe I would bring my daughter to her first day of school and just dump her, knowing she can’t hear? What sort of mother do they think I am? I’m insulted, offended.

But they go on to tell me that Hannah wouldn't respond during class. And talking to her one-on-one didn't help either. “It's as if she's in a world of her own,” they tell me.
I explain that Hannah had just visited her doctor and that we were told everything was okay.

Their reply: Hannah may remain in the class for now, but she'll have to be tested. Within the week, the state will be in to evaluate my daughter.

Worry torments me throughout the week.
What will the evaluators find? What will this mean for Hannah? For our family and our life together? It's all I think about.

For one long, agonizing week, everything Hannah does or doesn't do, every odd or even not-so-odd behavior, sends a shiver of fear through me. Yet I watch her continually, unable to do anything else. She's my baby. So whatever the signs of trouble might be, I look for them, even though I am afraid to see.

These days are endlessly dark, deep. And yet we still don't know what's going on with Hannah; we have no diagnosis, nothing concrete.

But somewhere inside me, I do know. I have known all along.
It simply would take someone else's eyes to help me recognize what was in front of me. It's not just Charlie and I who notice Hannah's differences anymore. Now others, who don't even know her, see them too. And suddenly the differences are real.

This, I suppose, is what is meant by living in denial. For us, the specter of trouble had always been just that, a fleeting sensation, a brief and blurry notion. Then, ever so faintly, the light finds its way in. Dim though it is, that's all it takes. Now here Charlie and I stand with possibility looming large. No, we don't know what's wrong with Hannah yet, just that something is. And that is enough.

The bottom drops out from under me, and I am helpless.

A therapist rattles a tambourine next to my daughter's ear. Nothing. No recognition from Hannah at all. Then she bangs a drum; still nothing. Hannah doesn't play it herself either. Not standard behavior for a two-year-old. Her heavy breathing
concerns them too. My first step, they suggest: take Hannah to an ear, nose, and throat specialist for a hearing test.

That I can do. Their suggestion actually comes as a relief to me. Could it really be her hearing, as her teachers first suspected? In fact, despite the concerns I'd brought up with several doctors, not one had tested Hannah for a hearing loss, or even suggested it. Maybe hearing loss really is the problem.

As it turns out, Han has “glue ear,” a painless condition in which sticky fluids collect behind the ear. For Han, this condition caused a 30–40 percent hearing loss in both ears. A significant loss, I'm told, one that could certainly account for her delayed speech. As fall settles in, Hannah is fitted for tubes and undergoes surgery to remove her tonsils and adenoids. As we expect, she comes through it like a trooper. The doctors are optimistic, and so are we. We should see a changed Hannah, Charlie and I believe.

Within a month of her latest surgery, I find Hannah sitting alone on the couch, holding a cup
to her ear. She shakes it, shakes it again. Then a brilliance washes over her face. For the first time in her life, my daughter hears the sound of ice.

I’m overcome with joy, with gratitude. At last, we have our answer! No more digging, no more doctors. Hannah went into her fog because she couldn’t hear us. This I can handle. She will come back to us, I’m certain; it will just take some time.

With the intent of helping Hannah's progress, we research some early-intervention schools on Long Island. There are three, and the state early-intervention agency insists I visit all of them. At one, an all-day school geared mainly to autistic children, I’m shocked by what I find. The school uses the applied behavior analysis program, which basically stresses learning through repetition and reward. The idea behind the program—which has been used with good results by many—seems okay, I decide, but the school uses food to reinforce right behaviors. It looks to me like people training dogs. What’s worse, I see teachers putting vinegar on children's tongues to get them to say “no.”
Before leaving, I meet one of the school’s pupils, an adorable five-year-old girl with autism. “Hi,” she greets me, and we chat for a few moments. Then, as I’m leaving, she says, “Hi,” again. My heart sinks. Often, my guide explains, children with autism can’t differentiate between meeting and parting. Driving away, I have no trouble saying goodbye to the place. My Han will never go there. I don’t want her in school all day, and besides, it’s not the place for her. All she needs is a nice nursery school, I think, and a little time to catch up.

In the meantime, while she is being evaluated, we have kept Hannah at her original school. Her teacher there asks us to meet her at Chuck E. Cheese’s for lunch. A friendly gesture, but one with a purpose, I discover. As the teacher puts it, she needs to see “what Hannah is like outside of the classroom.” She watches as Hannah flounders around in the ball pit.

Now I’m really uncomfortable. Why are we doing this? The teacher watches my daughter's
every move, studying her like an object under glass. “Sometimes,” she says finally, “I think yes, Hannah is definitely autistic, and sometimes I think no way.”

A shock wave of panic floods my body. Suddenly I have trouble hearing, breathing. And I can’t think. What did she say? Autistic? In my head a resounding “no” echoes. Then I hear my own voice, “No, no way,” and I’m snapped back into my nightmare moment.

“Han’s not autistic!” I keep telling myself on the drive home from lunch. “She can’t be. She’s my girl, and I know her.” I’m furious with Han’s teacher for even bringing up such a subject. Hadn’t we settled this whole thing? Hannah had a hearing impairment. We fixed it. It’s been only a few weeks. Can’t they cut my daughter some slack?

But I already know that the issue won’t go away on its own. A few days later, I call for an appointment with a neurologist, as Hannah’s teacher suggested. There’s a cancellation, and the
doctor can get us in at 4 p.m. Fine. Maybe this will put an end to all this talk. We make the appointment.

I expect to have a good hour or more with the doctor, but when we show up, the waiting room is packed. I know from experience that Hannah won't last. I can't make her wait—not this long—she just won't tolerate it. But if we leave, who knows when we'll get in again? Against my better judgment, we stay.

At 5:30, when the doctor gets around to examining Hannah, she's having a screaming fit. Despite my and the doctor's efforts to make her more comfortable, Hannah won't settle down. She refuses to make eye contact with the doctor and instead stares at her closed hand for most of the visit.

From this, the neurologist issues her diagnosis. “Pervasive developmental disorder. Not otherwise specified, that is what your daughter has,” the doctor tells me. A stabbing pain grips my chest. I look at my little girl. “What does that mean?” I ask the doctor. “How did this happen?”
The doctor offers me some explanation, though I don't fully understand it. Something about Hannah's condition falling within the spectrum of autism. But all I keep hearing is “autism.” I leave in shock, with more questions than answers.

Driving home, I'm seized with terror. They're not right, I try convincing myself. Hannah just needs to get used to hearing again. The doctor's diagnosis can't be accurate, I reason. Hannah was hysterical in that exam room. It wasn't Hannah's fault. What did that doctor expect, making us wait so long? She couldn't have gotten it right. Hannah just can't be . . . The PDD label is just a tag. Just a tag they use to make sure she gets the services she needs.

But the terror never leaves me, because the truth is undeniable. Hannah sits right behind me, strapped snugly into her car seat, riding along on the way home to break the news to Daddy.
During Hannah’s exam, I had requested that she receive an MRI in order to rule out my fears that someone, at some time, had dropped Hannah on her head. To our relief, the test shows normal brain activity. And within a few days, we enroll Hannah in the school for children with autism, where I swore she would never go. But still, Charlie and I aren’t completely convinced of the neurologist’s findings. It seems to us too easy to sweep her into such a broad category of disability, especially after the doctor had spent so little time with her. But we’re being whisked through the system nonetheless. If Hannah’s new school isn’t right for her, we’re told, we’ll find out soon enough.

The professionals’ approach seems almost cavalier. This is my daughter we are talking about, a special human being, a precious life. And we have to make her life right.

Night after night, I can’t sleep. Hannah has started getting up at all hours, and she’s impossible to put back down. On the nights she crashes
and stays in bed, I wake up at 2 a.m. anyway and stay up, crying for hours. My poor little girl, what are we going to do? How did this happen? Why her? Hasn’t she endured enough? And what will she become? The thoughts spool through my mind; I’m incapable of turning them off. I’m so afraid for her.

Every morning she cries as she leaves on the bus. Not even three years old, and my baby takes a bus to school. I’ve been told by school administrators that it’s best for her to take the bus at least one way to or from school in order to learn independence. And shouldn’t I believe them? But I can’t stand to hear her crying. It’s worse when I come to pick her up. I find her screaming uncontrollably. This is killing me.

I can’t put her through this anymore. There has to be something else, something better.

And so were we ushered into the unfamiliar world of special needs parenting.

Eventually, we pulled Hannah from her school and moved from Long Island to New Jersey,
which offered a broader selection of early-intervention schools and where we hoped to find more support. Charlie had grown up in Jersey, and I had moved there from New York when I was twenty-three. I had met Charlie there when he was the running backs coach with the New York Giants, and it still felt like “our” place. Our new home also had room for a barn where we could keep horses, one of my passions. Both Charlie and I, but most importantly Hannah, would be more comfortable there. We had reached the point where we didn’t really care how quickly Hannah caught up but only that she wasn’t miserable throughout the process. We found a more suitable preschool, where the children had varying types and degrees of special needs.

I did what I had to do and kept the wheels turning. But my grief was still fresh. My mind churned away for hours at night, and I always ran through the same questions, carrying on the same conversation with myself and with God. I spent more time than I should have trying to figure out how this had happened to Hannah. Did I do something
during my pregnancy? Did we unknowingly expose her to a harmful substance when she was a baby?

Only now, in retrospect, do I see that my struggle with questions about how and why this happened was the most right and natural response I could have had to Hannah's diagnosis. It's pretty much the first and only response, I've since learned, that parents of children with regressive-nature disorders have after witnessing such abrupt changes in their child. It's literally like going from day to night. Hannah was there, and then she wasn't. So I looked long and hard for a culprit.

Then, too, I doubted my own ability to care for Hannah. Could I handle what was ahead for us? We, the doctors included, weren't even positive that Hannah had PDD. I remember thinking that I could spend the rest of my life raising a child who does nothing but bang her head against a wall. And what if she were to hurt me or herself? Would she ever really know I was her mom? I wasn't at all sure I was capable of this degree of sacrifice. And truthfully, I didn't want to find out.
Yes, I resented our situation. Han and I had been cheated out of our time alone with each other. We were supposed to be going to the zoo and having breakfast together. Instead, she was in school all day. I wanted things back the way they were. Poor Hannah had been through her rough times—her birth complications, her surgery—and had survived them. We didn't need this mess, this hurt.

And that's where my streaming thoughts always carried me: to the lowest point, to the core, to the hurt.

During the day, I could fill up my mind and my time with business and activity. But at night, with my body at rest, and weary from the day, the feelings flooded in. How I missed my sweet girl, her tranquil nature, her laugh, her little hands holding on to my legs while I cooked dinner. We had reached the point where she hardly paid any attention to me.

I experienced such anguish that sometimes I found myself wondering if it would have been better had Hannah's disability been evident at birth. At least we wouldn't be tortured by the memory of
what used to be. And what about Hannah? Did she know what was happening to her? Did she long for her old self the way we did? My thoughts nearly drove me crazy.

But there were other factors stacked against me, too.

Charlie had always been my rock, and still was. But in his new position as offensive coordinator for the Jets, he worked around the clock. Plus he spent hours commuting between work on Long Island and our home in New Jersey. When he couldn't make it home, he slept on a portable bed in his office. Handling Hannah's situation was hard enough on him. On top of that, every night I wore him out with more worry and talk of Hannah. And, as happens in many families in our situation, things got bumpy.

I finally realized I was only adding to the weight of Charlie's load. He was in mourning, too. He had “lost” his daughter, just as I had. But he also faced the threat of losing his wife.

I backed off. The last thing Charlie needed was worry that his wife was going over the edge. So I
just kept inflicting my thoughts and fears silently on myself.

I did have friends around, but no one really understood what I was going through. And out of both of our families, the only people who ever reached out or stepped up to help us were one of my nephews and my mother. Thank God my mom was with us. She’d give me a break sometimes, letting me go ride my horse, even though her radiation treatments wore her out. But I spared her from seeing my worst self. Of course, I didn’t want to put any more mental strain on her; she was already burdened enough by her own poor health.

When we had lived on Long Island, I had attended a support group for parents of children with autism and PDD, but only once. Most of the parents there had older children, and they told stories without happy endings. One mother described her teenage son just staring at his upheld hand for hours and then screaming. I couldn’t handle stories like that. I never went back.
When we moved to New Jersey, I assumed I'd find more of the same, so I shut the door on the idea of ever finding help in the community. I had left that first meeting so dejected and scared; I wouldn't make that mistake again.

I tried reading about various disorders and syndromes, but my mind always shifted away from the text. Next I searched the Internet but still struggled with my concentration. I didn't find the help I needed there either.

I did have little Charlie. And it was because of him that I kept it together at all. He still needed his mother. And I so needed him. Without meaning to, I hung all my hopes on him. For him, I dreamed big things. Those dreams kept me going, like the warmth from a small flame. He brought me such joy, a precious speck of stardust among the ashes. We needed each other. And so we kept each other's fires glowing, fanning and fanning when the embers got low.

It wouldn't be enough.

Months went by, and the daily discouragement I felt over Hannah's situation never subsided. It
was always the same, just as she was always the same. At her new school, some children with severe PDD and autism had made great strides with their therapies. Amazingly, they seemed nearly “normal” as they moved into kindergarten. And so I had held on to the slim hope that Hannah would be there someday. But she wasn’t anywhere near that point yet, at least not then. Every day she was the same when she got up in the morning. And in the middle of the night. And when she got off the school bus in the afternoon.

In fact, Hannah slipped further and further away from me, it seemed, as the weeks and the months dragged on. Once, when I was visiting Hannah’s school, I just happened to cross my daughter’s class in the hallway. “Hi, Hannah,” I said. But she kept on walking. I waved. I smiled. The other children waved and smiled back at me. But my Hannah, she just kept walking. She didn’t know who I was. She did not know her own mother.

My heart broke that day. That’s when I realized that my daughter, the Hannah I once had, wasn’t going to survive.
I settled into a deep and profound sadness. I told no one.

Blindly push ahead long enough, I discovered, and you’ll soon find yourself alone on the path—all others swallowed up in the distance you've put between them and you. The particulars of my life had driven me into a remote outreach, and I couldn't find my way back.

In time, my isolation was complete. I became my own prisoner, immobilized and hopeless.

Driving around town with Hannah one day, I barely avoided what could have been a serious collision. I was so distracted, my mind so consumed with thoughts of Hannah, that I could hardly focus on anything else, not even driving.

In those first moments after our near miss, I realized the hold my thoughts had on me. They were relentless. And I wished I could just wipe everything out, just for a little while, just long enough to feel the briefest relief from the fear of our situation and the constant barrage of my own thoughts.
My isolation was deceptive, I later learned. Certainly I didn’t get there on my own, but I made the mistake of staying. I crawled in, looking for a place to hide where my grief and longing and torment and fury and confusion wouldn’t have room to find me. Someplace away from the world and all its reminders of what we had lost, away from those daily barbs and the pain. But, really, I retreated into something far worse. To refuse my suffering, I had refused life.