CHAPTER 1

THE DIAGNOSIS

July 1994–June 1999

ANA

Our son Austin devoured books. Not reading them, eating them. His twin brother, Christian, also ate strange things, like string and fabric. We had no idea why they were doing it, and when we asked questions of other parents and pediatricians, nobody else seemed to understand it, either. Don't be too alarmed, we were told often when the twins were between two and five, all children are different and can be puzzling with the phases they go through.

None of our early concerns diminished the joy we felt at having three healthy and happy sons. The twins were a bit of a surprise, coming along eighteen months after our first son, Jonathan. In my mind, we were on track and blessed in so many ways. I always had been one to dream about the "perfect life" I wanted to live. Even when I was a little girl, I tried to envision how my life would be. This was it. In fact, this was even better than I could have imagined. I was delighted to be a stay-at-home mom while Curt continued developing his car dealership in suburban Seattle after having retired from his eight-season NFL career. I was so proud of him; he had such success

as a running back with the Seahawks, and now he was applying the same kind of dedication and hard work to his car business.

When the twins reached two, their personalities started changing. They always loved hugging and being held, and wrestling around with Jonathan, but at that point they started pulling away from physical contact. It was as if the activities they loved had started irritating them. At first, I rationalized it as them beginning to find their unique personalities. We'd never had twins, so maybe their gaining distance from us was common for children in multiple births. Their behavior worsened as they grew, though, to the point where I was certain this was more than just one of those cranky stages that kids go through. Persistent gnawing on chairs and tables and windowsills was nothing we'd seen from Jonathan.

I'd never seen kids with such energy, either. They almost never slept. So naturally, we didn't, either. We couldn't take our eyes off them, especially Austin, who could be so quick. Sometimes he'd reach down to pick up something off the sidewalk, such as a worm, and if we didn't get to him fast enough, he'd eat it. Austin climbed everywhere. He was fearless, like a tiny daredevil lacking any sense of caution or concern for self-endangerment. He had no innate fear of getting hurt. He also had a particular knack for finding ways to get things he wanted even if we had hidden them for his own protection, and for figuring out how to sneak away and get into mischief.

These behaviors were unnerving for us as parents, but one thing beyond those concerns really alarmed us: the twins were both growing increasingly angry and aggressive. They were hostile with each other, with Jonathan, and with us. Hitting, slapping, biting. Ever more frequently, this simmering anger would erupt into inconsolable rage. Life became a succession of crying fits, which were so frantic and so all-consuming that we started calling them "meltdowns." I believe that parents, especially mothers, have great insights into who their children really are, deep down,

and can truly identify what makes them tick. But we were at such a loss to understand Austin and Christian, and so many unexpected behaviors were coming at us that it became hard to sort through it all. Even when they were calm, the twins no longer interacted and communicated normally, sometimes sitting alone, sullen.

Almost every night after we would put the kids to bed, Curt and I would huddle in our room for a few quiet moments to compare thoughts, to sort through the events of the day, to try to make sense of it all. It was like we were debriefing each other, as if we needed the other's thoughts to verify what we were seeing and feeling. Curt assured me that all of this chaos wasn't just in my head, that I wasn't imagining what was happening. Our discussion would end, and, exhausted from the day, we'd give each other a kiss and try to drop off to sleep, only to be awakened within minutes by one of the twins banging on something. We were in a cycle of anxiety-fueled days and sleepless nights.

For almost three years, we worked our way through the lengthy list of pediatricians, giving one doctor after another the full account of the twins' behaviors. One doctor handed Austin a tongue depressor to occupy his interest while he asked me a few questions. By the time the doctor charted his notes and looked back at Austin, he had chewed the stick down to nothing. Austin *ate* the tongue depressor. Chewed it up completely. He'd done it almost as if on cue to illustrate my claims.

"See, that's what I'm talking about," I told the doctor. He was stunned. Said he had never seen anything like it. But like all of the twins' exams from roughly age two through almost five, the doctor's assessment resulted in no definitive diagnosis.

As time went on, the twins' language skills failed to develop, and instead of gaining new words, they began constructing a confusing vocabulary of their own. Early on, doctors told us this sometimes was a pattern common to twins, or might be the result of my speaking both English and

Portuguese, my native language growing up in Brazil. I thought it might be good for the boys to grow up bilingual, as it's so much easier to learn languages at an early age. But I stopped the Portuguese immediately after talking to the doctor who thought it might be contributing to the twins' lack of verbal development. That might have been the first time that I worried that I was causing them to be behind schedule in their benchmarks. That was it—I was at fault.

Nothing we tried to correct the decline in their speaking and reasoning skills helped, though, and soon Austin and Christian were well below the charts in almost every developmental metric—language, socialization, cognitive awareness. Children are expected to be making sentences by age three, to play cooperatively by four, to know two thousand words by five. Curt would always examine the charts in the pediatricians' offices and notice that the twins were nowhere near the expected benchmarks. This deficit was especially true for Christian. The doctors said that developmental problems in twins can be particularly significant for a less-dominant twin like Christian. Male children tended to be slower with language, anyway, they assured us. We weren't reassured, though; our older son, Jonathan, hadn't had any language trouble or any of these other curious behaviors. Meanwhile, their tantrums grew more and more spectacular.

Even a quick trip to the store could lead to an emotional detonation. I remember going to Lowe's one time to get some supplies for yardwork. I wanted to be brave enough to take the three boys to the store and put them in the cart and go into the gardening area. There was a fairly strong smell of fertilizer when we walked in, and I can only guess that this is what set the twins off. They started screaming so loudly I had to turn around and get out of there. For the rest of that day—and many days after that—I felt like the worst mother in the world. How was it that I couldn't even take my boys shopping without creating such a scene? I couldn't help but notice how other shoppers looked at us—how they looked at me!

It wasn't surprising that people in the store would be curious. Before the twins, I had never seen children act like this, either. But their looks were so judgmental. What was I doing to these kids that upset them so? I must be mistreating these kids to get them screaming so loudly!

Jonathan, in the same circumstances and environment, continued to be so calm and easygoing. Only on rare occasions would the twins' behavior upset him. I could understand his anxiety when he would get caught in the middle of some of these meltdowns. The outbursts were frightening to Curt and me, so it had to be terrifying for a little boy. As our stress compounded with every sleepless night and troublesome day, Curt and I continued to second-guess ourselves. When doctors couldn't come up with anything, we were left to assume it was us, we were doing something wrong. It had to be some flaw in our nurturing. Didn't it? It had been one thing to think that I had inadvertently created the problems with their language skills, but it was far more hurtful to think that somehow I was causing my twins to be so unhappy and angry. As deeply as I looked, I couldn't find answers, and I beat myself up over it—especially as my young sons became more volatile.

As the twins' size and mobility increased, so did our challenges. Curt and I began to sleep in shifts so one of us could be on watch 24-7. We didn't have a choice. They'd get up in the middle of the night and be all over the house, getting into things, even climbing on furniture and then falling off. Those can be dangerous situations, so we had to beef up our defenses. We changed their bedroom doorknobs to put the lock on the outside so we could keep them in their room at night. We would set up a baby monitor so we could always be listening. At one point we tied their little toddler beds together; for a short while their being close to one another at night helped them sleep a little better. That didn't last, though.

During the day, the meltdowns grew more frequent, and nothing could be done to console them. When we tried to comfort them, they'd either strike out or withdraw further. Christian was particularly short fused. And when he wasn't upset, he was almost completely disconnected, lying in a corner, precisely lining up his toys, focused on it as if it were the most important thing in the world. We tried to get smarter, to become behavioral detectives, looking for clues and patterns in what would trigger a meltdown or cause them to disconnect. I started keeping track of everything we had done during the day and everything they had eaten. But there never was a common stimulus we could pinpoint.

Still, as confused and concerned as we were, no emotion was greater than our gratitude for the gift of these boys. It was difficult to be thankful specifically when we were in the heat of a meltdown, but all the while we knew what a blessing they were. Having already lost one child, we learned that nothing could be taken for granted. It wasn't ever the pressure or exhaustion that was most troubling to us; it was the realization that our boys were in a kind of pain we couldn't understand. For some unknown reason, everything was so hard for them. We felt we had to keep pushing doctors to find a way to help them.

In the early summer of 1999, as the twins were nearing five years old, we moved to Camas, in southwestern Washington. Curt had taken over a car dealership in the growing suburb of Portland, Oregon; it seemed to be a better business opportunity, and the boys were still young enough that the move wouldn't be disrupting. The general manager at the new dealership took special interest when Curt happened to mention some of the twins' behaviors. He had a friend whose child had some behavioral issues and had been helped by seeing a doctor at Providence Portland Medical Center. He referred Curt to this doctor.

On June 10, 1999, exactly one month after we moved to Camas, we took Austin to see this doctor. This morning was overcast and gloomy. The doctor had told us that she wanted to see the twins one at a time, so we arranged to have a sitter come watch Jonathan and Christian. Taking Austin first made sense to us. He was the more advanced of the twins. He had slightly better language and social skills than Christian. His vocabulary was better, even though it consisted of just five words, all curiously related to Disney movies. We'd been stunned when we heard him say "Pocahontas" at a time when he couldn't say "mama."

The doctor was pleasant and professional—a specialist in developmental pediatrics. She talked to us about the boys' behavior for a few minutes as she watched Austin playing with toy cars on the floor nearby. She called to him, trying to get his attention, and tried to get him to look her in her face. Austin didn't respond. He was that way with us, too, when he was focused on something. Sometimes it would be as if he had withdrawn behind a curtain.

But that's how little boys are, right? They're busy. All little boys are like that, aren't they? I expected the doctor at some point to start a thorough exam, to check him over completely. Take some tests, perhaps. But she needed none of that. She had seen all she needed to see and had heard all she needed to hear from us. She leaned toward us and announced: "Your boy has autism." Her diagnosis seemed so abrupt, especially after so many doctors had made so many examinations over the years without coming up with a diagnosis.

At that time, awareness of autism was limited. I was certainly an example of that. The only frame of reference I had for autism was the movie *Rain Man*, with Dustin Hoffman. I thought back to the scenes of him flapping his hands, screaming and avoiding everyone's touch, and then suddenly getting so loud and hostile. It was a frightening image. I remembered the character having great math skills. Our boys hadn't shown any signs of those kinds of specific skills. Then I

remembered that Hoffman's character spent his life hidden away from his family in an institution. I panicked at the thought. Would they try to do that with our twins? Would they take away our boys? I was lost in the horrible image of people coming to get our kids. Curt's mind must have been spinning, too, because neither one of us said a word in response. The doctor surely picked up on our confusion. "Your boy has autism," she said again.

I looked at Curt. His face was blank, his eyes were wide. We both looked down at Austin, playing quietly on the floor. He couldn't have this thing . . . this *autism*. After all the examinations both of the twins had, there was no way this doctor could see Austin for a mere few minutes and be so certain of the diagnosis. She'd done nothing more than watch him play. I was really proud of him; he'd been very good and well-behaved and quiet. He hadn't thrown a tantrum or had a dramatic meltdown. How could she be so sure just from watching him play, and from our brief descriptions of his behaviors?

Yes, he was slow to speak and had some unusual habits. We thought maybe it was ADHD, we'd heard about that, it was all over the news. And there were pills for that, right? That wouldn't be the worst thing. But autism? Like Dustin Hoffman in that movie? We still hadn't responded.

"I'm sorry," the doctor stressed again. "Your son . . . has . . . autism."

"What did I do wrong?" It was the first question I asked the doctor.

"No, no, it's not your fault," the doctor said.

"How could it *not* be my fault? I'm their mother," I said. I'm sure it sounded like I was pleading for her to tell me it was my fault. I wanted to defend Austin, to take the blame for whatever was wrong. I started making excuses for him, listing anything I could think of that I might have done to cause the twins' behaviors.

I told her that I had gone through such deep emotional lows, after earlier pregnancies, that I had postpartum depression; maybe I'd been so torn apart by those experiences and I hadn't given the twins enough attention. I could do better. I promised I would. I was to blame, not the boys. I could be a better mother.

"No, it's not your fault," the doctor said again. She was very compassionate when she heard me trying to assume blame. "There was nothing you could have done. And there's really not much you can do now. There is no cure."

The room went silent, except for Austin's playing, as Curt and I took in those words: *no cure*. I thought, *Oh, no, if Austin has autism, and he's our healthier son, what will this mean for Christian?*

I don't remember a thing the doctor said after that. I wanted to leave before she told us something else hurtful and unfixable. I can't remember any instructions about what we should do next. Were there more specialists to see? What would lie ahead for the boys? What would lie ahead for us? I'm sure she must have told us some of these things, but I was in shock, and confused and afraid. I was numb, in fact. That was what it felt like: I'd gone completely numb.

Then came denial. Curt and I had been given so many theories by so many doctors for so many years. Why should we believe that this doctor got it right? We should schedule an appointment with another specialist as soon as possible. We should keep trying until somebody got it right. We couldn't stop until we got a diagnosis of something we could cure.

The drive home was thirty minutes. Or maybe it was three days. I don't remember anything about it. I was dazed, and still absolutely certain that this was all my fault. Curt was silent next to me in the car. Maybe he was also haunted by the idea that somebody might try to take our twin boys from us, to institutionalize them like the autistic Rain Man. Curt would never stand for that.

It would get very ugly if somebody tried to take Curt's children from him. But Curt had gone so quiet, in such deep thought, that it frightened me.

When we got home, I raced to the computer and typed out a search for the word *autism*. I started seeing lists of behaviors that matched so much of what we'd experienced with the twins. I knew immediately the doctor was right. Autism was obviously the right diagnosis. There was no question. I was suddenly amazed—and upset. How was this the first time we'd heard the word mentioned? I no longer wondered how she had spotted it so fast, but why so many others had failed to spot it at all.

I kept going from one website to the next, taking notes, starting what would become a decades-spanning study of the disorder. From that moment, I knew we were going to be in for a long battle, but it was a relief in two important ways: first, at least we finally had a name for it, and second, maybe it wasn't my fault after all.