Not Fade Away: A Memoir of Senses Lost and Found

Rebecca A. Alexander, Sascha Alper
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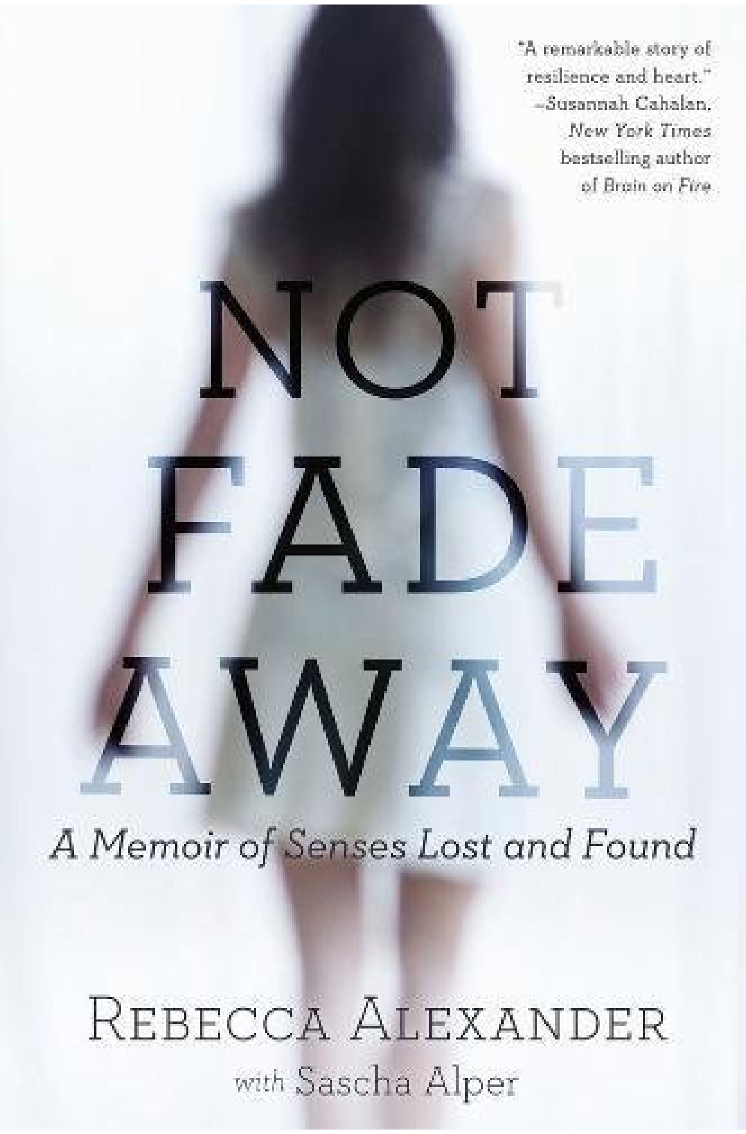

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Rebecca A. Alexander, Sascha Alper : Not Fade Away: A Memoir of Senses Lost and Found before purchasing it in order to gage whether or not it would be worth my time, and all praised Not Fade Away: A Memoir of Senses Lost and Found:

21 of 21 people found the following review helpful. Full of wit, humor, love and truth.By R.S.Having the privilege of knowing author Rebecca, I could write for hours about her perseverance, how inspiring and strong she is and how to me she is essentially a superhero. But none of these things, (as related to her disabilities) define who she is for even a minute, nor do they define this book.What starts as a truly unique couldn't write this sh*t if you tried kind of story,

quickly reveals itself to be full of humor, humanity and the universal truths and questions we all face. I felt as if I was sitting across from Rebecca being happily bombarded by her contagious humor and zest for life. Her personality, honesty and relatable experiences jump off each page, prompting the reader to consider not only their own blessings and challenges, but the larger questions about being the best friends, sisters/brothers, lovers and people we can be.We all stand to learn so much from those like Rebecca who are brave enough not only to live life SO large but also to share each moment so honestly with the world. Every anecdote in this book is a reminder of how adaptable, resilient and downright loving we can all choose to be when given the choice. Not a light read to be sure, but as only Rebecca can, this book takes the scariest and loneliest aspects of our lives and creates space for laughter, love and hope. A GREAT read.4 of 4 people found the following review helpful. A journey that's full of challenge and hopeBy skatzeRebecca Alexander's "Not Fade Away" is a journey that's filled with a full range of emotions from sad and shocking to funny and hopeful. At 19, she received the news that she had Usher Syndrome Type III. It's a rare genetic mutation with profound consequences--loss of sight and sound. But, even at 12, when an ophthalmologist told her parents she would need a guide dog by 20, Rebecca never simply gave in to the diagnosis at hand. Along the journey, we see the familiar life of many teenagers including possibly ourselves. From her parents' divorce to her first romance to moving far away for college, so many events in this young life ring true. And she manages to give us a valuable insight into a world that so few of us understand. As a child, I recall a bizarre conversation that seems more common now than I realized. I was asked if I had to lose one thing, sight or sound, which would it be? Rebecca never had the choice. Yet, she takes the most out of life she can and truly practices the concept of Carpe diem-Seize the day!Above all, Rebecca Alexander's book left me feeling more humble than I could imagine. But, it also left me with such a wonderful feeling of hope. It's a wonderful book to read and share. Of all the books I have read over this past year, Not Fade Away ranks at the top!0 of 0 people found the following review helpful. Amazing Book. Amazing PersonBy EarclopsFirst off the reviewer four down below me sounds like a real winner. My Lord... Second time reading this book. Flew through it the first time in one sitting and a year or so later after upon my recommendation my neighbor read it which motivated me to pick it up again and read a few sections. With ultimately led me to reading it again and appreciating it even more. Extremely moving and important book. Now if you're born without a soul then perhaps give the aforementioned reviewer a call. The two of you can pick up a pair of magnifying glasses and singe ants for a few hours.

The inspiring and moving memoir of a young woman who is slowly losing her sight and hearing yet continues to live life to its fullest potential. Even a darkening world can be brilliantly lit from within.Born with a rare genetic mutation called Usher syndrome type III, Rebecca Alexander has been simultaneously losing both her sight and hearing since she was a child, and she was told that she would likely be completely blind and deaf by thirty. Then, at eighteen, a fall from a window left her athletic body completely shattered. None of us know what we would do in the face of such devastation. What Rebecca did was rise to every challenge she faced. She was losing her vision and hearing and her body was broken, but she refused to lose her drive, her zest for life, ormaybe most importanther sense of humor. Now, at thirty-five, with only a sliver of sight and significantly deteriorated hearing, she is a psychotherapist with two masters degrees from Columbia University and an athlete who teaches spin classes and regularly competes in extreme endurance races. She greets every day as if it were a gift, with boundless energy, innate curiosity, and a strength of spirit that have led her to places we cant imagine. In Not Fade Away, Rebecca tells her extraordinary story, by turns harrowing, funny, and inspiring. She meditates on what shes lostfrom the sound of a whisper to seeing a sky full of stars, and what shes found in returnan exquisite sense of intimacy with those she is closest to, a love of silence, a profound gratitude for everything she still has, and a joy in simple pleasures that most of us forget to notice. Not Fade Away is both a memoir of the senses and a unique look at the obstacles we all facephysical, psychological, and philosophicalexploring the extraordinary powers of memory, love, and perseverance. It is a gripping story, an offering of hope and motivation, and an exquisite reminder to live each day to its fullest.

A remarkable story of resilience and heart,Not Fade Awayfollows Rebecca Alexander as she must navigate the world cursed with a rare genetic disorder that will one day rob her of both sight and hearing. Bereft of self-pity, funny, and bursting with honesty,Not Fade Awaywill get its hooks in you. I promise that by the end of her story, you will fall just as in love with Rebecca as I have.Susannah Cahalan, New York Times bestselling author of Brain on FireHer eyes and ears may be declining, but Rebeccas sense of self is sharply focused and profoundly tuned. By sharing her life, she has enriched mine and will yours, too. I love this woman.Meredith VieiraThere is a saying that goesyou never know how strong you are until being strong is the only choice you have. Rebecca Alexanders indomitable spirit spills out on to the pages of this incredible memoir. She will lift you up . . . the way she did for me.Hoda Kotb, New York Times bestselling author of Ten Years Later and Hoda, and Emmy-award-winning anchor of the Today showAn honest and eloquent look at life . . . Alexander emphasized the importance of embracing the here and now, of being present and grateful for the gift of life, in whatever shape it might take.Kirkus sProfoundly inspiring . . . [Rebeccas] ability to find so much to be grateful for after being dealt such an unfair hand challenges those of us with far fewer hardships to treat each day as a gift.Publishers WeeklyWise and realistic instruction in intentional living, grace, and overcoming obstacles great and small.BooklistAbout the AuthorRebecca Alexander is a psychotherapist in private practice, a spin instructor, a volunteer, and an athlete. She grew up in California and holds two masters degrees from Columbia, one in Public Health and one in Clinical Social Work. She lives in New York City.Excerpt. Reprinted by permission. All rights reserved.1Even though the doctors office was warm, I was freezing. A nineteen-year-old California girl in the midst of my first winter at the University of Michigan, I couldnt shake the cold that seemed to seep into everything. Though my hair and many layers of clothes had long since dried from my wintry trek through piles of mounting snow to the schools medical campus, I could still feel the chill in the constant ache down my leg and into my foot that never quite went away, making my limp even more pronounced.The office was spare and bright, and as I sat there, aimlessly looking around, legs tucked under me as I absently rubbed my stiff ankle, I thought about how many rooms Id been in just like this one. Days of tests and waiting, and more tests, and more waiting. This time I was here for the ringing in my ears, a relentless noise that had followed me for weeks, perpetually making me feel as though I had just left the loudest rock concert imaginable. Sometimes it completely drowned out other noises; at other times it whined incessantly in the background, keeping me awake at night, making me feel as though I was losing my mind. I knew what it was calledtinnitus, from the Latin word meaning to ringbut that didnt come close to describing what I was experiencing. It felt as though it was coming from inside and outside of my head, reverberating against my eardrums, something so obviously real that it seemed impossible that nobody else could hear it. When someone spoke to me, no matter how quiet it was around us, I felt like I needed them to raise their voice above it, the way they would if a fire engine were screaming by, or, better yet, speak directly into my ear. Please just let this go away, I kept thinking. What I didnt know at the time was that the ringing would never go away, that it would become my constant companion, and that in time I would learn to tune it out almost completely, a noise so familiar that I would sometimes have to strain to hear it at all.The door opened, and a doctor who appeared to be in his midforties walked in, followed by a few awkward-looking residents who quickly jockeyed for place around him, all trying to get a good look at the patient. The doctor, brisk and forthright, asked if they could stay while he went over my diagnosis with me. I nodded, smiling at them, feeling bad because I could tell that things were not good, and that they were going to have to listen to the doctor give a diagnosis that none of us wanted to hear. But they averted their eyes from my gaze, looking busily down at their clipboards, not yet having mastered the specialists casual smile: persistent, even in the face of very bad news. Though we werent aware that anything was wrong until I was twelve, it was there all along, lying in wait, showing itself in ways too subtle at first to notice. Ours was always the fun, boisterous house, the one all of the neighborhood kids wanted to hang out at, full of laughter, music, and roughhousing. My brothers and I were athletic: heedlessly racing, chasing and slugging it out when we fought. When our friends came over we would take countless screaming, bumpy rides in our sleeping bags down our long stairway and run wildly through the house. All of which probably made it harder to notice my clumsinessthough I was always the one tripping over things, banging into them, getting hurt. Being the only girl of the three of us, I shook it off, determined to be as tough as my brothers were. Even though Daniel and I were twins, while Peter was three years older, I always felt like the youngest, trailing after Danielbrilliant, athletic, beautiful Dan, already the superstar of everythingdetermined to try to keep up.In ballet, too, I was the clumsy one, awkward and off-kilter. In my pink tights and tight bun that I brushed incessantly to keep smooth, I was so eager to be graceful. But no matter how hard I tried I could never maintain my balance while holding my positions or float across the floor like the other girls. My stern, ramrod-straight instructor scolded Rebecca so often that I began to sneak out of class, hiding in the dressing room and eating my snack of Goldfish crackers in an attempt to avoid further humiliation.There were other signs, too, like the way I would turn my head sideways to watch TV, cocking my left ear toward it while looking out of the corners of my eyes, or the way I seemed to tune out sometimes, especially when I sat in the back of the classroom, leading my teachers to refer to me as a dreamer, which even then I knew was code for not paying attention. But none of this was out of the ordinary enough to catch anyones attention in our busy, noisy household.Really, though, it goes back so much further than my childhood, long before Daniel and I floated safely together inside my mother, a yin-yang of boy and girl curled against one another, when no one could have imagined the terrible and wonderful things growing inside of each of us. Back to Eastern Europe, most likely Kiev, where both of my parents had ancestors. Their numbers shrunk from countless pogroms, cousins would marry, and carry with them a single mutated gene that ended up here, inside of me, invisible, until at twelve I started having trouble seeing the blackboard. Although our house was a loud one, with rarely a silent moment, as a younger child I remember it as mostly joyful noiselaughing, talking, and lots of singing. We each tried our best to be more clever than the next, knowing that it pleased our parents, rapid-fire jokes and witty retorts tossed back and forth. My mother had at one time sung professionally, and we would often crowd around her at the piano, belting out show tunes as dramatically as if we were on Broadway, until she would stand up and lead us singing and dancing up the stairs to do our homework. Quiet felt so strange to me that I used to feel uncomfortable when I was alone, turning on the television or music for noise, much happier and better able to relax with plenty going on around meso different from now, when silence often feels like my salvation.That all changed when I was ten, a couple of years before we started to notice my vision problems, when a new noise started creeping around our house. At first it was barely noticeable, angry whispers through gritted teeth. Eventually my parents fights grew louder, screaming matches where my brothers and I would race in, pleading for them to stop or trying to entertain them, anything to make it go away. By the time they started to notice something was wrong with me, they were already separated, caught in that hazy trying to work it out phase, which we could all tell wasnt working.My dad had taken me to the optometrist after I told him that I was having trouble seeing the blackboard at school, assuming that I needed glasses. The doctor had frowned through much of the exama look Ive gotten to know well over the yearsand at the end of the appointment told my dad that he had seen something in the back of my eye that needed to be examined more thoroughly, but he didnt have the equipment or the expertise to properly evaluate it. So we were referred to an ophthalmologist, and then another one, and another. We went to see specialists at the University of CaliforniaSan Francisco and Stanford, and eye charts were replaced with increasingly complex equipment and tests, one of which required me to have hard lenses with wires coming out of them attached to my eyeballs, while another had me staring at bright flashing lights as long as I could without blinking. I kept thinking, All this just to get glasses?Each time, I waited for the doctor to come out with a smile, to nod and tell us that hed figured it out, that things were just fine, theyd fix me right up. In one test I was given several times, I would sometimes press the button to signify that Id seen the little flashing light even when I hadnt, wanting to make everyone proud. I wanted to ace these eye tests, to have everyone tell me I had done a great job, to get to leave and pick out a cute pair of glasses, go home and stop thinking about my eyes and my parents fights and their worried glances at me. I wanted to worry about twelve-year-old things, hanging out with my friends and spending hours on the phone with them, talking about boys, what we would wear to the upcoming middle school dance, and whether or not one boy or another liked us as more than just a friend.Eventually, the diagnosis came. The doctors told my parents that they thought I had something called retinitis pigmentosa, an incurable, inherited disorder that meant the cells in my retina were slowly dying. They explained that I would most likely be blind by the time I was an adult, and my parents had to decide how to break this news to me. How do you tell your child this? What words can you possibly find to explain this to a young girl? I cant imagine their heartbreak, knowing that someday their daughter would no longer be able to see them, or her brothers, or the world around her.From the start my mother was convinced that I should have all the information, that it was my body and that the more I knew, the more I could prepare and find ways to help myself face, emotionally and physically, what lay ahead. If I knew, she argued, I would understand why some things were hard for me, that it wasnt my fault that I couldnt see a tennis ball coming, or had so much trouble in dance, or couldnt see my way to the bathroom at night without banging into things. She knew this was a challenge I had no choice but to rise to and fully believed that even at my age I should be allowed the responsibility of understanding.My father vehemently disagreed. I was, in his eyes, still his little girl. He was terrified that I would hear what he referred to in a whispered hiss as the b-wordblind. He thought that I should be given the information slowly, over time, so that I could digest it. He had all of the literature from the hospital and the Foundation Fighting Blindness sent to his office, so that I wouldnt see any of it. At first all that I understood was that my vision was getting worse, and that it would become even harder to see at night. The rest would come slowly, the progression of the decline in my vision and hearing subtle enough from day to day that the realization, when I was young, never hit me full force. Im not sure, though, that even if my parents had told me everything from the start, I would have been able to comprehend it. How could a twelve-year-old possibly imagine going blind? At nineteen, back in the warm office in Michigan, the doctor sat down across from me, the interns flanking him shifting uncomfortably as he delivered my diagnosis. He spoke kindly but directlyno sugarcoating here: I was going blind and deaf.He told me it was a genetic disorder, one as of yet undocumented in the way it presented in me, but he had his suspicions all the same. Usher syndrome was his hunch, the symptoms that characterized it being simultaneous hearing and vision loss, though thus far he had only seen it affect people much younger, who were either born deaf and blind or had it present in early childhood. At that point none of these seemingly trivial details mattered to me, it was only the first sentence that I heard. The words pounded like a drumbeat in my headblinddeaf blinddeaf blinddeafdrowning out even the tinnitus. Still I tried to smile, nod at the right times, always be the good patient.Looking back, it shouldnt have come as a shock. It wasnt the first time Id heard blind or deaf. I knew that my vision was deteriorating more quickly, and my hearing was getting worse, too. Maybe I hadnt been ready to hear it before, but this was the first time that a doctor had laid it all out for me, making sure that I understood. And I did. For the first time I actually really heard it. Me. Blind. Deaf. No cure, no stopping it.I tried to think, to ask him questions about what I should expect and how fast it would progress. But they were all met with a gentle shake of his head and a simple, Im sorry, we just dont know. When we were done, I smiled, thanked him, and stood up. I stayed composed, said good-bye to the other doctors, and walked out, trying not to let my limp show, knowing that they must have pitied me enough already. I left the hospital, surrounded by great walls of shoveled snow, but this time I hardly noticed the cold.By the time I got back to my dorm, I knew what I would do with what I had just learned: nothing. I didnt call my parents immediately or go find Daniel, somewhere on campus, no doubt surrounded by a throng of friends and admirers. I went back to my room and took off my hat, shaking my long dark hair around my ears, making sure that it completely covered my hearing aids. I knew that I would still take them out and slip them under my mattress when I brought a guy back to my room, that I would do everything I could to compensate for my diminishing vision without talking about it. Sometimes it felt like a character defect, the same way it had when I was twelve. If I had just done better on all those tests, maybe my parents wouldnt be divorced, maybe I wouldnt have had the accident, maybe somehow I could just rewind it all and not be here, knowing what I was going to lose. Which, at the time, felt like everything.2Ashkenazi genetic disorders are common. Tay-Sachs, a devastating, progressive disease of the nervous system, is probably the most well-known, but there are many, and its estimated that one in four people of Eastern European Jewish ancestry is a carrier for one of them. These disorders come from a recessive genetic mutation, and, since genes come in pairs, if only one is mutated, you dont get the syndrome, but youll carry the gene with you. There are now simple blood tests for many of them, since, if both parents are carriers, there is a 25 percent chance that the child will inherit it. If only one parent is a carrier, it is harmless. Well, harmless being a relative term. Maybe dormant is a better word.Usher syndrome is rare enough that most people have never heard of it. It was named for the British ophthalmologist Charles Usher, who in 1914 discovered a common defect among sixty-nine deaf-and-blind people that hed studied.Children who are born with Usher syndrome type I are profoundly or completely deaf at birth; suffer severe imbalance due to vertigo, as their inner ear doesnt function properly; and usually dont benefit from the use of hearing aids. By around ten they start to lose their sight and then generally go blind very quickly.Type II is a little less severe. Children are usually born with some hearing loss but tend to have normal balance and generally keep at least some vision until their teens.My Usher, type III, is the least severe, which makes me comparatively lucky, if you look at it that way. And why not look at it that way? Any vision or hearing loss I had at birth was undetectable. The onset is slow, and subtle at first, and you are not generally blind and deaf until you are an adult.There was a time before I was living with the constant reminder that I was going blind and deaf, and for that I feel incredibly grateful. My mother felt guilty about not noticing my symptoms sooner, but since there was nothing that she could have done, it seems better to have had those blissful years of ignorance. It wasnt even possible, until a long time later, for our family to be tested for the gene, because at that point, nobody could even prove its existence. There were years where my parents didnt worry, didnt fear for their daughter, and didnt feel the heartbreak of knowing the things that I would lose, or might never have.For me, those were years of not being treated differently or feeling isolated, of having a chance to gain some sense of myself before this became part of who I was and who I would become. I feel so lucky that my disabilities didnt define me as a child and for what my eyes and ears have had a chance to experience. I have been able to see so much beauty, to read, to look into peoples eyes, and to hear music and laughter and the voices of everyone I love. I have created memories that will stay with me long after my eyes and ears have lost their ability to capture new ones.3A normally sighted person can see one hundred eighty degrees without turning her head. Today, I can see less than ten. The scientific explanation for retinitis pigmentosa, or RP, is that the retina, made up of photoreceptor cells, those rods and cones we learn about in science class, die. But the better understanding of what its really like is described by its common nickname, donut vision. I have a donut-shaped ring of blindness floating in my field of vision, and the donut gets bigger and the hole gets smaller every day. I have a sliver of vision left on the outside of the donut, at the outermost edge of my peripheral vision, and I can see straight ahead through the hole. But everything else, all of the donut, is gone. Im left with about a square foot of vision directly in front of me, and every day, a little bit more of the world is taken from me. It sometimes feels like the end of one of those old Warner Bros. cartoons on TV, where Bugs Bunny sits in the center of the screen waving good-bye as the picture becomes an increasingly smaller hole, until its finally gone, leaving only blackness. Thats all, folks.For a while, when my eyesight first started to deteriorate, if I was somewhere familiar my memory would fill in what I couldnt see. When I was younger I would move my eyes rapidly from side to side, scanning to be able to piece together a complete picture. I still do this, but as my vision loss has progressed, the donut hole becoming increasingly smaller, I can no longer overcome the blind spots. People now appear in front of me as if out of nowhere. Im unable to see them approach me from my periphery, and then suddenly there they are, in the tiny center hole of my vision. Its like a startling and unpleasant magic trick, one that I never get used to.Often, my brain creates made-up images in an attempt to compensate for the vision I no longer havefor a long time, I kept a frying pan by my desk at home because when I was at the computer, my brain kept projecting a peripheral image of a man walking through my apartment, or sometimes standing right at my shoulder. With a huge gasp, I would jump out of my chair, and then, like in a horror movie, he would be gone.When Im sitting across from someone in anything but bright light, I can no longer see their full face. I cant see their expressions: whats going on between their eyes and their mouth, how their cheeks are moving or the arch of their eyebrows, the subtle shake or nod of their head. I can see pieces, but never the whole picture. If Im introduced to someone in a dark, noisy roomlike a dimly lit bar or restaurantnot only do I usually miss the name of the person Im being introduced to, I generally have no idea where theyre standing, and I dont know where I should be sticking my hand out to greet them, so I just give it my best shot. I usually get it wrong, and sometimes I dont even know if Im meeting a man or a woman. Once, in a crowded club full of pounding music, a friend introduced me to a guy she knew and left me alone with him while she went to get us drinks. I leaned in toward him a few times to comment on the music and the crowd, despite the fact that I could barely see or hear him. Im not sure when he wandered away, or if he said good-bye, but I kept right on talking, and then reached out to touch his arm at one point and realized that, for at least a few minutes, I had been talking to a large column next to our table. Before Id even had a drink. Luckily, I couldnt see enough to note the reactions of the people around me. Though really, Im so used to not seeing or mishearing people that Im almost beyond embarrassment. When something like that happens, I have to laugh. Whats the alternative? The doctors who diagnosed me thought Id be blind by the time I was thirty. Im thirty-four now, and every day that I wake up and can still see is a gift.Every day, the cartoon hole closes in on me, and I push back against it with all my might.4The first lie I can remember telling was when I was seven years old. It was late one afternoon, and I heard the faint, magical tune of the ice cream truck. Whenever we started to hear itand sometimes, unimaginable now, I would even be the first tomy brothers and I would drop everything and perk up our ears, like dogs intently focused on a sound in the distance. Wed stay frozen until the tune became loud enough for us to realize that this was our chance, and then wed chase each other up the long flight of stairs from the backyard into the house directly to our piggy banks, grab our precious coins, and jump down the stairs two or three at a time, flying out the front door just as the ice cream man was slowly cruising by our house.On one such afternoon I raced in and opened my piggy bank, and found nothing but a few dark brown, tarnished pennies lying there. I thought quickly, and right after I heard Danny race back down the stairs, I ran into his room to borrow some of his change to buy my ice cream. I didnt know if hed find out, but I knew that no matter what I would deny it at all cost. Of course he noticed, and my mother asked me later that evening if I had taken his money. Though the Good Humor strawberry shortcake ice cream bar I had eaten hours before weighed heavily in my stomach, I was sure that if I just kept denying it, it would mean that I wasnt really the one who had done it, so thats exactly what I did. I denied it, despite there being no way that anybody else could have taken it, despite the fact that Im sure they all knew it was me. It didnt matter, because I knew I couldnt bear the disappointment in my mothers voice if I admitted it. I already felt like a huge disappointment to my mom for not being the little girl she wanted me to be.If you asked my mother, she would say that I was the most beautiful, precious, perfect little girl. And she would mean it. She would say that she couldnt be more proud of me, that I am extraordinary and wonderful, that I have done anything a fully sighted and hearing person could do and more. And she would believe it with all of her heart. But that was never what I thought. I knew I could never be anything like my mother, who could do anything and everything, and do it all with grace and charm. She was so beautiful, and feminine, and competent, and there was a part of me that thought I wasnt what she wanted in a daughter. I was sure, though, that I knew exactly what she did want: for me to be just like my best friend, Melissa Neuwelt.Melissa was perfect. She was little and tidy, with small, slender hands, and she played the piano beautifully. She had lovely features, a tiny nose, and absolutely no freckles. She was very smart, well behaved, and polite to a fault. She was any parents dream child. Of course, my mother adored her. And so, of course, I bullied her when she would come over, and when she threatened to tell on me to my mom, I locked her in my bedroom, barring the door. The minute I let her out she ran directly to my mothers room and leapt straight into her arms. As I watched my mother comfort her, I felt terrible and guilty. But I also hated her, for being able to be so good and honest all the time.I, on the other hand, saw myself as clumsy and lumbering, dreamy and messy, too sporty. I tried to be what I thought my mother wanted me to be, but I knew deep down that I wasnt. For as long as I could remember I had felt like I had to be someone different from who I was. And I was sure, even at seven, that I just wasnt good enough. I was sneaky, and I lied, and, even if other people didnt realize it, I knew that I wasnt a good girl.Where do we get these ideas about ourselves? In my practice as a psychotherapist, I see people every day who are still trapped in the patterns that they learned when they were young, the things that they believed about themselves as children remaining with them every day. I knew that there were differences between my mother and me, and because I so desperately wanted to be like her, I was sure that every difference was a fault.When I turned eight, my mom threw me a doll party. This must have been her idea, because I was not one of those girls who carried her dollies everywhere. But once she said it, all I wanted was a Cabbage Patch doll for my birthday, and they were sold out everywhere. That was at the height of the insane Cabbage Patch craze, and they were impossible to find. Of course, Melissa had one of the preemies, the most sought-after Cabbage Patch dolls of all. She brought it to my party, carrying it like a real baby and looking darling in her pretty dress sprinkled with tiny little flowers. There were doll centerpieces, doilies, and Cabbage Patch plates and napkins, all as girly as could be. This was not the party I would have chosen, but I did my best to play the part. My mom came to the table and taught us lullabies to sing to our dolls. The irony was that while the other girls had their little dolls, I had Montgomery Moose, Daniels favorite stuffed animal from the Get Along Gang. My mother sang in her beautiful voice, and all the little girls loved it, except me. There is a home video of this event, which shows Melissa holding her baby in just the right way, gently stroking her perfectly swaddled little preemie as she sings sweetly to her. I am sitting at the head of the table in a big chair that Danny is sharing with me, looking off somewhere, not paying much attention to the goings-on, Montgomery Moose resting listlessly in my arms. Danny had a Western-themed party. I had more fun at his.I wasnt a particularly smart child, but what I lacked in intelligence, I made up for with my imagination. I had such an active world in my head. I know now that when my teachers said that I was a daydreamer or had my head in the clouds, some of that must have been because I couldnt see or hear them as well as I should have. Still, they werent wrong. I liked my imaginary world much more, because I could be anyone that I wanted to be. I could take all of the things that I thought were wrong with me and replace them with beautiful ones. I would do this when falling asleep at night, because I was terribly afraid of the dark and suffered from nightmares. For years I slept in Daniels room, because I had seen Friday the 13th at a friends house when I was far too young and refused to sleep alone. Then I taught myself a trick where I would replay the same happy story again and again in my head until I fell asleep. When I was young I would fantasize about dancing as Clara from The Nutcracker, and as I got older I would imagine that a boy whom I liked was about to kiss me, and as soon as he leaned in toward me, Id replay the scene over and over, until I was asleep.My imagination was not exclusive to my dreams. I spent years of my childhood telling lies that Id created so vividly in my head that even I believed them. They were never malicious, and as a young child I mostly told them to avoid getting in trouble, but they came easily.As I got older, my lies became more elaborate, and, like dominoes set up one after another, each one led to more lies as I tried to cover them up. They were absurd, too, and totally unnecessary, but I always felt an overwhelming need to make myself seem better than I was.In seventh grade I remember talking on the phone to a guy I liked and was trying to impress by telling him that I was related to Cindy Crawford, thinking somehow that this might make me worthy of him. It sounds absurd now and I can laugh about it, but at the time, I was desperate for approval. I just thought I needed something to make me seem better, cooler, different.I told another guy whom I was trying to impress that I was going to be doing a photo shoot for Seventeen magazine and that I needed to choose a guy to be in it with me. I wrote down a list of questions to ask him about what hed want to wear and how hed want to be positioned in the shoot. I sat in the kitchen on the phone, twirling the phone cord as I actually wrote down his answers to these questions, nearly believing the ridiculous things that I was saying. I remember at one point a group of these boys called me and made fun of me for the lies Id told. And just as I had when I was a little girl, I denied, denied, denied.Perhaps this is part of why, when we found out that there was something wrong with my eyes, it didnt surprise me as much as it might have. Instead, it confirmed what I already knew about myself. I wasnt like other people. I had been right: I was deeply flawed, and I was never going to be perfect.All of the lying was useful in one sense: It prepared me for the much bigger lies that were to come. I was well practiced by the time I was hiding my hearing aids, hiding my vision problems, and still doing everything I could to try to be just like everyone else.Then I started to steal. My friend Jamie and I took lipstick from the drugstore one day, and when we found a cigarette on the ground while walking home that afternoon, we hid under the deck in my backyard, smoking in our bright stolen lipstick. When I was a teenager I started stealing more, from stores like J.Crew and Victorias Secret. It was a release, a high, and I felt exhilarated every time I got away with it. There was a part of me that felt like the world owed me something. That was how I justified it as I got older. I was just evening the scales.Of course, the world doesnt owe me anything. It doesnt owe any of us anything. It was me who owed the world, and myself, something: to be better than that. Though thats a lesson that I couldnt yet comprehend, one that I had to learn over and over again, until it finally stuck.5When I was a little girl I loved going to visit my mothers mother, Grandma Etta, in Santa Fe, New Mexico. I adore Grandma Etta, who is independent and free-spirited to this day, at ninety-two, still taking her morning swims in Lake Michigan and wearing beautiful Indian saris for festive occasions. When she would read to us she could do any accent and bring every character to life. My favorite was when Grandma would read me Eloise. She would capture her exuberant, naughty, childish voice perfectly, and I would sit, mesmerized, wishing she would go on forever.I knew that we were getting close to Grandmas house when I began to bounce gently in my seat to the sound of the tiny rocks under our tires, which meant we were at the beginning of her driveway. An insignificant sound, but one that I loved and can still remember so clearly.We would often go at Christmastime, and even though we were Jewish, on Christmas Eve Mom would put up little stockings for us, letting us enjoy a few of the perks that our friends did. Then we would walk down the pebbled roads, where tea lights in white paper bags would be lined up on either side to celebrate the holiday, and down into the town, where the Native American women laid their jewelry out on blankets. They were in an array of vibrant colors: the gorgeous range of turquoise greens and blues, bracelets and barrettes intricately beaded in red and green and yellow. We watched the ceremonial dance performances and chants, the men in their beautiful headdresses moving to the beat of their powerful drums. I loved how different the colors were from those of Oakland and Berkeley, with their heavily paved roads and towering trees of eucalyptus, oak, and redwood. Here, the backdrop for the bright colors and stones was the subtler colors of the Southwest, earth tones of adobe, purple, and brown.In the evening I would sit on the porch swing, with Grandmas dog, Tilly, a loyal German shepherd mix rescue dog, at my feet. I would absently stroke her with my toes as I watched the sun set in a brilliant wash of orange, red, and purple, and as the evening breeze picked up, the bells on Grandmas porch would start chiming. The bells and the sunset and Tillys warm body beneath my feet filled me with so much joy.The last time I remember seeing a sky full of stars was on one of those visits, when I was nine or ten years old. Once the sun had set, and the dark had brought in the chill, we would bundle up in our sweatshirts and sit outside of her little adobe house and look up at the universe filled with tiny pinpricks of light, the whole sky ours to see.Today I live in Manhattan, where no one is able to see the stars anywaybut whenever Im lucky enough to be in a place where theyre visible, Im sometimes able to see the very brightest ones. One, or sometimes two if Im really lucky, though whomever Im with assures me, when I ask, that the sky is full of them, twinkling diamonds in an inky-black sky. And this comforts, rather than distresses, me. To be able to see just one makes me so happy. I can still see a star, millions of miles away! The sky is still full of them, I have enough vision to see one, and my imagination can fill in the rest. Someday, Ill have to rely on my memory to conjure them, but I will have taken the time to look, and to be grateful.For me, there are so many experiences that are limited or already gone, and so many more will besome very soonthat it is impossible not to feel lucky now, while I still have them. I think that I am probably more grateful for that one star than I would be if I were fully sighted, looking at a whole sky shining with them.6My brothers and I all remember our family, and our childhood, as an idyllic one. We were always close, physically affectionate, rolling on top of one another like puppies, fighting to see who could be the wittiest, be the funniest, get the most attention. My mother would come home after a full day of work and cook us a homemade meal, sing to us, and play the piano, and coordinated our busy schedules to and from soccer and basketball practice and piano lessons. My father was loud, funny, and gregarious. He was tall and muscular, and when we were younger the three of us used to beg him to pick us all up at once and try to carry us around. There was nothing that frightened me more than when he raised his voice in anger at us, a rare event, but one that I dreaded. Our parents looked beautiful together, and I loved to look at pictures of the five of us hung around the house, my father next to my mother, dwarfing her, with his huge hand resting on her tiny shoulder, Peter, Danny, and I in front, grinning. I would run my fingers along the glass, stopping to rest the tip of one on each tiny face, and know with an absolute certainty that we were a perfect family.The night my parents told us they were getting separated we had sat down to an early dinner, so used to my parents strained conversation at this point that we barely noticed their silence as we chattered on about our day, talking over one another. They told us that after dinner we needed to go up to their room so that we could have a family meeting. We never had family meetings, and I remember nervously looking back and forth between my parents, who sat at either end of the kitchen table, not looking at us or at one another, trying to imagine what they possibly needed to speak to us about that couldnt be discussed right there at the dinner table. After we had cleared the table and helped clean the kitchen, Peter and Daniel raced and roughhoused their way up the stairs while I lagged behind, for once not feeling the need to keep up.I had always loved my parents bedroom. The lingering scent of my moms perfume, my dads shoe polish, and the crisp smell of his dry-cleaned work shirts greeted me each time I entered their room. Danny, Peter, and I would often lie on their bed in our PJs, making funny faces into the reflective brass globes that sat atop the bed frame, our grossly distorted features reflecting back at us from the round shapes of the balls, keeping us in hysterics until we were writhing in pain from our laughter. We loved to wake them up when we were little, racing in after Saturday morning cartoons to beg for my moms French toast, or her matz-n-egg scramble, a family specialty, accompanied by my dads fresh-squeezed orange juice. We would climb all over them, my mothers smell of sleep that I cherished and my fathers faint smell of Irish Spring mingling into the warm comfort of exactly where we belonged.That night, as we scrambled for our places on the bed, everyone wanting the middle, of course, my dad and mom slowly followed us in, closing the door behind them. My mom did most of the talking, and the only sentence I remember clearly is Your dad and I have decided to separate. Id only seen my mom cry a few times beforeafter a few of my parents fiercer argumentsand I would feel so incredibly guilty, watching her cry and not knowing what to do to help her. This time, though, my dad was crying, tooinconsolably. I had never seen him cry, and I felt so helpless and terrified. My big, strong daddy falling apart was not something I could comprehend; it didnt fit in with the world I knew and the father I loved. It felt so utterly wrong that I began to feel nausea rising along with my sobs. And I knew he wasnt just crying for himself, but for the unbearable pain they were causing us.What I didnt know then was that he was also crying out of guilt. Guilt that his own illness, his depression and maniawhich my brothers and I knew nothing of at the timehad helped push this into motion. Behavior that I would someday recognize in my brother, another illness carried down, probably through generations as well. Right then, though, all that I saw was that the two people whom I loved most in the world were preparing to tear our world apart.As my brothers and I pleaded and begged for them to reconsider or try to work it out, my father told us, between his sobs, that it was what he wanted, too, to try to keep our family together, to stay together and work on it. My mother was clearer. She told us that she could no longer tolerate her children running down the stairs to try to stop a fight between them. The last straw for her had been watching Daniel race into the dining room, shove himself between them, and plead, Daddy! Daddy! Please dont hurt Mommy! She couldnt bear the idea of us, her babies, feeling as though we had to protect her from my dad, and she did not want us to believe that our dad, who stood at least a foot taller than she did, could ever possibly hurt her.Danny, Peter, and I asked desperate, heartbroken questions, believing, the way children do, that we could somehow change the outcome of the adult world. Despite watching my parents fight more and more, I really thought we had the perfect family. My mother and father explained that they were going to first try a separation, though even then I could see by the look on my mothers face that this was my fathers idea. We would stay in our house, and they would alternate staying with us. That sounded horrible to me, but still, I clung to it like a life raft. Surely, I thought, they would come to their senses.This was the last time that we were all together in my parents room.