My mother became deaf at the age of thirteen months when she had a relapse of spinal meningitis. Doris Jean was a wiry, precocious child who’d already learned to say “mama” when the illness struck. She was up walking and talking again after her first bout, and the doctor in Greencastle, Indiana, decided she was so improved she didn’t need to have the complete series of injections. She lost her hearing during the second high fever. It was years before she said anything again and for the rest of her life few people would understand her when she did talk.

On an aberrantly cold March day in Montpelier, Indiana, when my father was two months old, his mother swaddled him in blankets and took him in her arms to her brother’s burial in Odd Fellows Cemetery. George had died of pneumonia. My father, Gale, developed what they used to call the grippe. The fever burned out his auditory nerves, leaving him deaf before he was three months old.

Two chance happenings. Accidents. Both that doctor and my grandmother had the best of intentions. Yet those two decisions changed the course of my parents’ lives and the lives of
their families forever. My father’s parents spent the rest of their days in self-recrimination. My father’s father, H.T. (short for Harvey Truemans), was the Evangelical United Brethren minister in a northern Indiana circuit. Soon after he found out that his firstborn was deaf (my father’s eldest brother, Garnel, was a blue baby and probably lost his hearing during childbirth), H.T. became a volatile and self-righteous preacher. Nellie May, my grandmother, having delivered seven children, two of whom were deaf, spent much of my father’s infancy grieving, then threw herself into church work. Her lobbying on behalf of the Woman’s Christian Temperance Union was particularly vociferous.

My mother’s parents, on the other hand, seemed bewildered by her deafness. Grandpa Wells—Chester—started out as a farmer and ended up a foreman in a saw-manufacturing plant. I don’t think I ever heard him use the word “deaf” all the time I was growing up. Instead, Grandpa looked to his grandmother—Ernestine—to take care of things. He felt she was the “smart” one—she’d had all A’s in school and he had dropped out to go to work. She did the bookkeeping for the farm and the grocery store he ran. Later, she would work in the library at DePauw University in Greencastle. During the days when her daughter was young, Grandma would read books about Helen Keller and fret about how she could teach her own little girl. In old pictures I’ve found, Grandma had the beauty and mystery of a silent-film star, but in later photos, both she and my grandfather had grown self-conscious and the lines of their mouths drew tight. During our Sunday visits, Grandma would sometimes sit, leafing through old albums, unable to choke back her tears. Eyes downcast, she’d once again describe what it was like when her baby was sick. “I just don’t know what else we could have done. We searched so hard. I wish there was a miracle…”

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Ten years after leaving for college, I was home again in Indianapolis, sitting in my parents’ blue-carpeted living room, listening. I could hear the squeak of the furnace, the blower over the stove my mother had forgotten to turn off, the high-pitched electronic squeal of two table lamps, the overly loud, slightly irregular ticking of their kitchen clock. As deaf people, of course, they couldn’t hear to silence the domestic sounds. Now that my sisters and I had moved out of the house, there was no one for the noisiness to disturb. To shut out the racket, I got up and turned off the blower and the lamps. Sitting back down in that darkened room, I realized that growing up in our house had been anything but quiet. It sometimes felt as if we were living in some kind of amusement park, lights flashing on and off the way they do around a carousel. Whenever the doorbell rang, a light in our central hall and another in the kitchen flashed on, and a loud buzzer went off for me and my sisters. (The man who’d installed our special doorbell was deaf himself and hadn’t known how discordant the sound was.) When the phone rang, lamps in the living room and an upstairs bedroom went on and off. If the call was for my parents, we would hear a foreign bleep-bleep, which meant we had to hook up the TTY, a teletype-telephone device with a coupler for the receiver that translated the bleeps into typed-out messages. If Kay or Jan or I answered the phone in the hallway, we’d race back to the family room, where the three-foot-high converted teletype stood. We’d gotten the TTY when I was in high school. It was an early model—newer ones are portable, with electronic readouts—and whenever a call was going over the machine, the house had all the clatter of a newsroom. My parents even had a pulsing-light alarm clock, which they often silenced not by turning it off but by pulling the pillows over their heads. (Some of their friends who were heavier sleepers had vibrating-bed alarms, systems that literally shook them awake.)
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Those weren't the only tricks we had. If my father was in the garage at his workbench, my mother would get his attention by switching the overhead bulb on and off several times in rapid succession. If my mother was reading the newspaper in the living room and he was sitting in his easy chair and wanted to talk with her, he would lightly stamp his foot on the floor until she looked up from her paper, at which point he'd wave his hand so she'd be certain which one of us was "calling" her.

Although my parents communicated solely in sign, even that language isn't completely silent. Signing is vivid, the hands often brushing against a shirt or thumping a chest. But if my parents were having an argument—easy to spot because of the velocity of their gestures—my sister and I would hear hands smacking hands. They could talk, but their words were unintelligible to anyone but my sisters and me. They used their voices simultaneously with their signs when they spoke to us. Otherwise, they talked only in emergencies or unusual situations. My mother has a voice that's soft and cooing as a mourning dove's, but she could nonetheless scold us roundly for coming home late. Her voice didn't carry, however. When she called out for us in the backyard, my name came out "loooohn." "Kay Sue" and "Jan Lee," names specifically chosen for ease of pronunciation, turned into unearthly "Kehzoo" and "Zhanli." Often as not, if we were in another room, my father would come get us, yet if he did call, the timbre of his voice, slightly higher pitched than Mom's, reminded me of a harpsichord, one note played over and over again. I've often seen people react curiously when they hear my mother and father talk aloud (thus my parents usually relied on the more nearly certain paper-and-pencil method). Yet as long as I've been around deafness—around my parents, their deaf friends, my deaf aunt and uncle—every time someone refers to them as "mutes" or "deaf and dumb" or "the dummies," a violent, reactive surge of anger rushes through me. Those terms seem to be uttered so derogatorily, they seem to be clumping everyone together in one small, neglectable bin. Besides, virtually no deaf people have problems with their vocal cords; they just cannot hear to monitor their own voices.

As I sat in the living room, I realized that if all my parents had to endure—and all my sisters and I ever had to hear—was a little name-calling, life would have been much easier. On the face of it, deafness seems to be a simple affliction. If you can't hear, people assume you can make up for that lack by writing notes, that you can pass your spare time reading books, that you can converse by talking and reading lips. Unfortunately, things are always more complicated than they seem.

Until they're about the age of two, babies are tape recorders, taking in everything that is being said around them. The brain uses these recordings as the basis of language. If for any reason a baby is deprived of those years of language, he can never make up the loss. For those who become completely deaf—"profoundly" is the term audiologists apply—during infancy, using the basics of English becomes a task as difficult as building a house without benefit of drawings or experience in carpentry. Writing a grammatically correct sentence is a struggle. Reading a book is a Herculean effort.

Nor is lipreading the panacea hearing people would like to believe. "Bed," "bid," "bud," and "bad" all look identical on the lips because vowels are formed in the back of the mouth. The best lip-readers in the world actually "read" only twenty-five percent of what's said; the rest is contextual piecing together of ideas and expected constructions. The average deaf person understands far less. Thousands of times during my mother's life when she misinterpreted what someone said, she watched the other person grow impatient or become angry because she seemed so slow. She'd learned early on that it was
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easier—not only for herself but for everyone else as well—if she simply smiled and nodded. We would all pay a price for that later on.

Neither of my grandfathers ever learned a single sign. My grandmothers and some of my aunts and uncles got down the fundamentals, but none of them were expert enough to carry on a regular conversation. From time to time they, too, had to rely on notepads and pencils to get their points across to my parents. Worst of all, though, was my grandfather H.T. When he wanted something conveyed to my father, he usually told Nellie May. “Tell the boy to chop some firewood,” he’d say, without even looking my father in the face, and then he’d turn on his heel and leave the room.

Helen Keller once said: “Blindness cuts people off from things; deafness cuts people off from people.” Never having a real conversation with your parents or with your children is a good example. Yet some of the isolation is more complicated than that. People stare, even gawk at you in public when you’re signing. And it’s difficult to have an argument or stick up for yourself with a hearing person. Strangers inevitably feel awkward around you because they don’t know how to talk to you. When people suddenly realize that you’re deaf, they feel so embarrassed—for you, for themselves, for the situation. And so often you’re just in the way. We watched people in the street try to pass my father as he is walking. “Excuse me,” they say, but of course my father doesn’t hear that. When they finally get past, they turn and glare.

In a family where there is deafness, guilt is a constant undercurrent, tainting relationships, sometimes even shattering that family. My own grandparents constantly exhorted me to “be good,” themselves feeling guilty for not doing more for their children, hoping somehow I would make up for things. They felt guilty for reasons they couldn’t make clear to themselves. Time and again I heard my grandmother Wells say she

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would give her own hearing to make her daughter “whole.” In her mind, deafness was some kind of divine retribution. My grandparents examined their lives over and over, wondering what it was that was forcing them to do eternal penance. The guilt feelings didn’t do anyone any good. It breaks my heart sometimes when my father approaches me tentatively with a small request. “Excuse me,” he signs, the curled fingers of his right hand lightly rubbing his left palm. “Could you please make a phone call for me? Would it bother you?” He feels guilty about needing help. And deep inside him, the guilt his own mother felt is still a burden to him.

It can’t have been easy for my parents to have to rely on their three daughters to conduct all their business affairs. I signed before I talked, and from a very early age I ordered for Mom and Dad in restaurants and explained what they wanted to clerks. When I was about eight, they began giving me their letters so that I could correct the grammar. I don’t think I ever minded doing anything they asked. (Like all children, I loved feeling important.) But in a few instances I was an unfaithful go-between. I could never bring myself to tell Mom and Dad about the garage mechanic who refused to serve them because they were deaf, or the kids at school who made obscene gestures, mocking our sign language. Not once did I convey the questions asked literally hundreds of times: “Does your father have a job?” “Are they allowed to drive?” Those questions carried an implicit insult to a family such as ours, which was proud and hard-working and self-sufficient. I reworded the questions if I had to interpret them. And I never allowed myself to think about the underlying meaning. What I admired about my father was his dignity, and my mother, her joy. I didn’t want to upset the fragile balance. Children need to look up to their parents, even if it means doing some rearranging.

I once talked to a woman whose mother was blind. Her most poignant memory of childhood was a day she helped her
mother, pushing her baby sister in a carriage, cross the street. She can still see the traffic heading toward them on the avenue as she focused all her strength into the arm guiding the carriage. She was struggling to remain calm. What was important was the appearance: making it look as if her mother was leading.

To the hearing world the deaf community must seem like a secret society. Indeed, deafness is a culture every bit as distinctive as any an anthropologist might study. First, there is the language, completely separate from English, with its own syntax, structure, and rigid grammatical rules. Second, although deaf people comprise a minority group that reflects the larger society, they have devised their own codes of behavior. For example, it’s all right to drop in unannounced, because many people don’t have the special TTY telephone hookups. How else could they contact their friends to let them know they’re coming? If a deaf person has a job that needs to be done—from electrical wiring to accounting—he’s expected to go to a deaf person first. The assumption is that deaf people won’t take advantage of each other and that they need to support their own kind. The deaf world is a microcosm of hearing society. There are deaf social clubs, national magazines, local newspapers, fraternal organizations, insurance companies, athletic competitions, colleges, beauty pageants, theater groups, even deaf street gangs. The deaf world has its own heroes, and its own humor, some of which relies on visual puns made in sign language, and much of which is quite corny. Because deafness is a disability that cuts across all races and social backgrounds, the deaf world is incredibly heterogeneous. Still, deafness seems to take precedence over almost everything else in a person’s life. A deaf person raised Catholic will more likely attend a Baptist deaf service than a hearing mass.

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It’s so easy for mothers and fathers to get along with their newborns, their tender, sweet-smelling babies. Then the world intrudes. And things get complicated very quickly. It was as if I’d been under anesthesia all the time I was growing up. I wasn’t even aware that I was struggling to balance so many worlds. I performed my duties willingly but I had blinders on—which is just as well, because once I left home and started sifting through all that had happened, I began realizing how impossible things had been for Mom and Dad, how hard things still were and how hard they would always be. Every day they met with constant, irritating reminders of their shortcomings, from the petty annoyance of not being able to ask for a cup of coffee in a restaurant, to the sobering knowledge that they couldn’t hear cars careening around corners, and that deaf people had been shot in the back by policemen when they hadn’t heard a command to halt.

Sitting in their neat, cozy house, Mom and Dad in their cocoon of sleep upstairs, I realized that what seemed as if it should have been different wasn’t. And what seemed as if it should have been the same wasn’t, either.