nothing special

[ the mostly true, sometimes funny tales of two sisters ]

dianne bilyak

“Rich in character, humor, insights, and love.”
RACHEL SIMON author of Riding the Bus with My Sister
nothing special
A DRIFTLESS CONNECTICUT SERIES BOOK

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nothing special

[ the mostly true, sometimes funny tales of two sisters ]

DIANNE BILYAK
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Front cover illustration: Easter photo of Chris and Dianne at their grandparents’ house on 1 Grant Avenue, Stafford Springs, Connecticut, 1971. Courtesy of the author.
TO MY FELLOW SIBLINGS who have their own stories, both lovely and difficult. May you find ways to be seen and heard.

TO ALL THE PEOPLE WITH DOWN SYNDROME I’ve had the pleasure of interacting with who taught me that it’s who we are and how we treat others that truly matters.

AND TO MY INIMITABLE SISTER, CHRIS BILYAK, thanks for making my life interesting and fun, for always singing with me in the car, for “liking me a lot,” and teaching me that dancing can solve most problems.
If the memory of pain haunts you,
and you live your life afraid to be in pain,
then you are in a disabled state.

STEPHEN KUUSISTO
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Author’s Note

When I asked my sister, my only sibling, Christine, a.k.a. Chrissie, Chris, or Christopher, “If I write a book with stories about us what should I say about you?” she answered:

1. I am very sorry I took Charlene’s chips last week.
2. I will earn my gifts and cookies and ice cream.
3. Christopher is right all of the time.

My response to number three was, “We’ll just see about that.”

Chris has Down syndrome. She doesn’t like to write much and reads on a first-grade level, so if one of us is going to chronicle the stories of our lives, both together and apart, it has to be me. I’ve tried to dig into her psyche and include her perspective as much as possible, but she has no interest in the examined life and gets annoyed when I prod. She can’t meaningfully consent to being depicted here, but then again, neither can my dead father, and he gets plenty of ink.

While my relationship with my sister is at the heart of this book, and for that matter, my life, this story is my own, shaped by my experiences and limitations. Fortunately, I’ve been able to align my memories and deepen my understandings with help from many people. My mother still starts most of her sentences with “your sister,” and then goes into a five-minute oration about something Chris did. Various aunts, cousins, and some dear family friends and former babysitters were willing to go back in time and offer their perspectives and what they remember.

When I first began writing down some of the stories that became this book, it was around the time I’d read Barbara Kingsolver’s The Poisonwood
Bible, a novel predominantly about sisters. The following excerpt stayed with me, “Desperate to save myself in a river of people saving themselves. And if they chanced to look down and see me struggling underneath them, they saw that even the crooked girl believed her own life was precious.” These words pushed me to continue to shape my writing into essays that I’d read in various venues.

On the occasions I dared to imagine I’d adapt the essays into a manuscript, and that the manuscript would be published as a book, I’d joke that it would probably instigate a lawsuit from the National Down Syndrome Congress alleging I’d violated my sister’s civil rights, and any royalties would be used for legal fees. News outlets would make me out to be a monster, while my sister would be seen as a victim and be elevated to a media darling. To make good use of her time in the spotlight, Chris would hire an agent, along with a manager, to coordinate her many invitations to speaking engagements and talk shows. Since she was used to having a staff administer to her needs, she’d be a natural at stardom.

In this counterfactual universe, she’d ask me to ghostwrite her self-help autobiography, You Do What I Say, and I’d have no choice but to obey. It would become a bestseller, and when Oprah Winfrey chose it for her book club, Chris would accompany Oprah to Canyon Ranch for a major detox and a meeting with the Dalai Lama.

I then pictured Chris and Oprah partnering with some members of the Kennedy family to start a retreat center called Down Syndrome Nation (DSN). Designed and operated entirely by people with Down syndrome, DSN would become a leader in intentional community living. Unlike other retreat centers, DSN would offer open snack bars, hug therapy, checker circles, meditative tidying, and life coaches who, instead of conducting planning sessions and improvement exercises, would offer only positive affirmations. DSN might start as a place, but it would become much more than that—a way of life, a method of thinking, a model, and a practice—not a way of doing, but of being.

I’d begin working at an indie bookstore where everyone would wonder if I’d met Oprah. After work I’d return home to write sad poems and fuss over my newly adopted cat. My sister might answer the phone when I’d call to indulge me for a few seconds of chitchat, but then she’d hand me off to one of her many assistants. On my birthday and for Christmas every
year, one of those assistants would send me a free pass for a retreat week at DSN and a gift card to T.J.Maxx.

These musings were mostly absurd, but there was some truth in there. Over the years, I’ve experienced being overshadowed by my sister, and neglected by my parents. If she was the “special one,” what was I? I’ve also felt uneasy about exposing these feelings, fearful of being judged by others if I told my truth. These were uncomfortable emotions, and I needed to work through them. But they weren’t my only feelings. I’ve also felt protective of Chris, delighted by her, and grateful for our relationship.

I want to be very clear that my sister is not defined by lack. “Disability,” as activists and scholars remind us, is a condition that arises because society fails to make room for the full range of our humanity, and gets hung up on norms instead of ways to support all people with the accommodations each deserves to live an inclusive life. My own life, in different but overlapping ways, has also been defined by external circumstances and expectations. I’ve allowed myself to be delayed, as it were, by a host of forces, and I’ve had to adjust and ask for help to meet those challenges.

For most of our lives, Chris and I have treated each other as equals. Like many typical siblings, we used to fight over everything and laugh over anything. We’re still prone to compete over the smallest things and tease one another mercilessly, even if it means making a scene. We are like two class clowns with a mafia streak—entertaining, unless you so much as look at us funny. Then, not only will we always defend each other, but we’ll stand together and find a way to make you pay.

DISCLAIMERS

Some names have been changed by the person’s request or for reasons of anonymity.

At the time of printing, this author used person/people/individual(s) with a disability or I/DD, and so on. These are accepted terms in the culture. I am sure it will change and evolve. No disrespect is intended.
part one

$C + D$
[early snapshots]
One of the only four pictures taken of us as a family (Dick, Dianne, Nancy, and Chris), circa 1968.
The Art of Losing

IT IS CLOSE TO MIDNIGHT. IT IS TIME FOR BED. I FOLD MY GLASSES AND PLACE THEM ON THE BOOKSHELF NEXT TO MY CHAIR. I CLOSE MY BOOK AND TOSST IT TO THE FLOOR. UNDER THE COVERS I REMOVE MY SOCKS WITH MY FEET AND PUSH THEM TOWARD AN ASSEMBLY OF OTHERS. I INSERT MY EARPLUGS AND TURN OFF THE LAMP.

MY FATHER IS THE CLOSEST TO ME, BUT ONLY IN PROXIMITY. HE’S 1.7 MILES AWAY. IF YOU WANT TO VISIT HIM YOU HAVE TO CROSS THE RAILROAD TRACKS TWICE, ONE TIME NEAR THE OLD MILL, AND AGAIN AFTER YOU ENTER THE CEMETERY. A BOX BEARS HIS BODY; HIS STONE, OUR NAME.

MY MOTHER IS ONE STATE OVER, 70.1 MILES AWAY. I KNOW SHE’S IN BED BY NOW, BUT HAVE NO IDEA IF SHE’S SLEEPING. SHE HAS INSOMNIA. EARLIER, I KNOW SHE STRUGGLED TO KEEP HER EYES OPEN WHILE WATCHING TV. IF I WERE VISITING SHE’D HAVE TAKEN OUT A BOWL AND SPOON, A BOX OF CEREAL, AND A MUG AND PLACED THEM NEAR THE COFFEE MAKER SO SHE WOULDN’T MAKE TOO MUCH NOISE IN THE MORNING BEFORE SHE LEFT FOR 8 A.M. MASS.

MY SISTER IS OVER AN HOUR AWAY, 57 MILES BETWEEN US AND 17.8 BETWEEN HER AND OUR MOTHER. SHE WENT TO BED AT 8:30 P.M., LYING ON HER BACK AFTER PUTTING HER HEARING AIDS IN THEIR CASE. FROM THE BATHROOM, HER NIGHTLIGHT SHEDS ITS FAINT AND DUSKY GLOW ACROSS HER FACE. ONCE SHE FALLS ASLEEP HER MEASURED INHALES AND EXHALES WILL SOFTEN HER ROOM AND EVERYTHING IN IT.

NOW, I’M REMEMBERING THE HOUSE WHERE WE LAST SLEPT UNDER THE SAME ROOF, THE HOUSE MY PARENTS HAD BUILT IN 1965 SHORTLY AFTER THEY WERE MARRIED, THE HOUSE WHERE CHRIS AND I GREW UP. MY PARENTS MET AT THE STATLER HILTON IN HARTFORD, CONNECTICUT, WHERE MY FATHER WAS THE NEW APRENTICE CHEF AND MY MOTHER WORKED AS THE OFFICE SECRETARY. MY SMITTEN FATHER LIED AND SAID HE WAS WRITING A BOOK AND WANTED TO HIRE HER TO TYPE IT. HE WENT TO HER HOMETOWN ONE SATURDAY NIGHT, SUPPOSEDLY TO DISCUSS THIS PROJECT, BUT REALLY TO WOO HER. HE TOOK HER TO THE ITALIAN RESTAURANT FREQUENTED BY THE
locals. The wooing worked. A year later they married in her town, at her church, and began to build their life there.

The house stood in the winding hills that stretched up from the area many townies used to call “Downstreet.” It was a red Dutch Colonial with a nice yard, in a nice neighborhood, in a town that had gone from bustling to bedroom once most of the mills closed and the passenger train stopped running in the late 1940s. Soon after they moved in, my mother, at age 25, became the last of her four siblings to have children, giving birth to my sister Christine in 1965. Three months later, my mother was pregnant with me. In 1966, I had the same due date as my sister, but arrived four days early. Chris and I are Irish twins.

When I can’t sleep I map out each room in that red house as I remember it—where the furniture was placed, which braided rug, handmade by my mother with wool from the town’s textile mills, covered each floor, what items we kept where: linens and towels at the top of the stairs, pencils in the chaotic junk drawer near the fridge, and in the dining room hutch, a wedding gift of barely used Lenox dishes.

Chris and I had moved out by the mid-90s. In 2003 my parents downsized to a condo and sold the house. When it was on the market again in 2016, my mother asked me to accompany her to see how it had been remodeled. When we arrived, I went straight to the closet in my old bedroom. It had been Christine’s bedroom first, and we liked to fill the space with pillows and cocoon ourselves in there. When we were four and five, we smuggled in crayons and colored on part of the scratchy white wall. Our mother never caught us. In 2016, when I slid the closet door open, I could still decipher our first story: faded lines and circles spelling out *We are here.*
When my sister was about two months shy of her fourth birthday and experiencing some motor issues, Aunt Barbara, my mother’s sister-in-law and a nurse, told my mother she thought Chris had Perthes disease, which is a rare hip condition affecting children.

My mother’s sister, my aunt Ginny, recommended Dr. Pelican, the pediatrician she brought her two girls to. My mother made an appointment, and because my father was away at work, her father brought her and Christine to the doctor.

My mother says that when Doctor Pelican entered the examination room and saw Chris sitting on the table, he took one look at her, and before my mother could even begin to discuss the possibility of Perthes, proclaimed, “When your sister referred you I wasn’t told your daughter was a mongoloid idiot.”

As the doctor inspected my sister, he droned on, delivering the kind of monologue that was culturally and medically acceptable for many decades, when people with disabilities were falsely considered uneducable, or even subhuman: “Have you considered putting her in an institution? That is what most people do since she will probably die before she is 18, and if she lives longer, she will only be able to do some menial job, like hairdressing.”

In shock, and not even sure what a “mongoloid idiot” was, my mother and grandfather exited the office with Chris and cried in the waiting room. Over the next month my sister was tested, and it was confirmed she had mongolism, now known as Down syndrome or trisomy 21. Soon after conception, fetuses with trisomy 21 spontaneously created an extra copy of chromosome 21 in every cell. My parents went to a geneticist at Yale to
Nancy and Chris, circa 1966.
each get tested, and to ascertain how my sister might have developed the condition. The conclusion? It was a fluke.

Sometimes it’s tough for me to grasp why no one had expressed concern about Chris’s development. Sure, she reached many of her milestones within the normal range and was just a little behind schedule with crawling, walking, and toilet training. And my mother was able to measure Chris’s progress alongside our many cousins, three of whom were born within a few months of my sister. But she also had some difficulty swallowing, and her speech was slow to develop.

In old photos, Chris often looks like a typical infant, baby, or toddler. But in some she exhibits certain vague disparities in her facial features that are common to those with her condition. Searching the web for the types of medical information so easily available today, I read that people with Down syndrome have “Eyes shaped like almonds, flatter faces, especially the nose, small ears, which may fold over a bit at the top, tiny white spots in the colored part of their eyes, and their tongue may stick out of the mouth. They may have small hands and feet with: A crease that runs across the palm of the hand, short fingers, small pinkies that curve toward the thumbs. They may also have: Low muscle tone, loose joints, short height, short neck, and a small head.” *

When I really concentrate, I can see how some of that does describe Chris. She has small teeth, a slightly tilted head, a crooked grin, and blue eyes that reflect light like still waters. Occasionally she has a sleepy expression that offers a cryptic mix of faraway and immediate. But mostly, when I look at Chris, I simply see my sister. And when she laughs in her high-pitched giggle, sometimes for no reason whatsoever, even at my expense, I laugh, too.

What mostly astounds me is the almost four-year gap between my sister’s birth and diagnosis. Some of the people I wish I could ask have already died, and others were unwilling to offer much. A couple of family members admitted they suspected something was different about Chris, but chose not to divulge their suspicions. Still, our family physician, who lived around the corner and made regular house calls, only admitted he’d

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known about my sister’s Down syndrome after it was confirmed by Dr. Pelican. He said he hadn’t informed my mother because he wanted Chris and her to have a chance to bond.

Perhaps it was because our town was less than 20 minutes from an institution that warehoused many people with disabilities, and as Dr. Pelican said, it was still common to isolate infants from their families in these places. I don’t know if either physician was aware of how much the children there were susceptible to neglect and abuse, and that such treatment kept them from learning and thriving, which worsened their conditions and shortened their life expectancies, often more so than their disabilities.

After Christine’s official diagnosis, what changed for my family? My mother says she mostly feared the unknown. This was new territory for her, and our rural Connecticut town was not filled with resources for families with kids who were differently abled. Nor was most of the rest of the country. Donna, a teenager next-door who babysat for us, remembers my mom crying a lot. My mother said my father distanced himself even more from us.

And how much was I aware that our family life was changing in response to my sister’s diagnosis? Prior to that, Chris and I were raised as equals, and then we weren’t. We were both considered normal, and then she wasn’t. Yet those first three years when I experienced my sister as only my sister, not my sister with a condition, fused a normative bond between us.

Soon after she was labeled, Chris started school a few towns away. From 7:30 a.m. to 1:00 p.m. weekdays, we were separated for the first time. I was glad to get an extra year of being home with my mother and I finally forged my first distinct memory of the two of us without my sister. Weekly, she took me to the town library where I sat in her lap and we listened to story hour. Carol, the children’s librarian, would read to us about Sal and her blueberries and Max with his warm supper waiting outside his door after his romp with the wild things. I’d pick out some books to take home and then stand on the wooden stool at the bubbler to slurp water for as long as I wanted while my mom checked out my books. Once outside, we looked both ways for oncoming traffic, and when it was safe we crossed the street holding each other’s hands.
Get in the Car

In those formative years our mother was forever in motion, like a wave advancing or retreating from our shores. She oscillated and reciprocated; there was very little stillness inside her. For me, it wasn’t always easy being the daughter of this motion. Sometimes the only way to handle her unpredictability was to keep a distant watch from dry and accommodating sand. If I tried to swim out, I might get stuck in the waves, or possibly drown in their undertow.

At home, Chris and I were aware our mother was there, but not always where she was; she was ubiquitous but peripheral. When we were in earshot, we’d know she was in the kitchen when we heard the buzzing of the rotary phone’s dial as it was pulled forward and fell back into place. She paced from room to room, tugging the curled cord behind her while conversing with friends, neighbors, family, and fellow members of the different organizations where she volunteered.

In order to survive raising two young children born less than a year apart, mostly without her husband to co-parent, our mother kept us in constant motion, too. She played ball with us and sang songs. She was silly, and if we were upset she teased us to make us laugh. She pushed us to always go one step further, to try a little harder and do a little more: climb one more stair, take one more bite, recite one more letter of the alphabet. We were reprimanded when we forgot to say our pleases, thank-yous, excuse-mes, and God-bless-yous. We had excellent manners.

On Sundays and holidays, since we all lived in town, our mother’s siblings and our cousins congregated for noontime dinner at our grandparents’ place. In our small town of 8,000 residents, the house was notable, white with black shutters and white pillars, built in the 1800s. I sometimes felt lost in the hubbub of our extended family, but more often, they insulated
me in a safe bubble. My grandparents had 19 grandchildren and four great-grandchildren, and with the exception of a couple of the boys, they all were accepting and kind, and Chris and I knew we belonged.

We kids would start a game of hide-and-seek in the finished basement, which smelled musty from heating oil and the exposed rocks of the foundation, or play pretend on “the big rock” outside. The big rock was also the setting for our favorite pastime, reenacting *Little House on the Prairie* with our cousins Lori and Lynn. I’d play Laura, a.k.a. Half-Pint, Lori was Pa, Chris was Ma, and Lynn was Mary. Pa narrated and directed us on the homestead, where we’d prepare mud pies and rhododendron salads, progressing through a whole week of pioneer activities in just a couple hours.

Our clannish ways were similar to a lot of town families, for whom immigration to America was still a recent memory. My great-grandparents left Italy and took a steerage ship from Le Havre, France, to America in 1907, but their son Geno chose to stay in his hometown with his grandparents and make the journey west on his own time. My grandfather was conceived in Italy and born in America. Since Geno decided to stay in Italy, it took 60 years, and a trip by my grandfather across the ocean, for the brothers to meet. Small wonder that, when he started his own family, Poppy, as some of us called my grandfather, kept his children close, even after they’d grown.

Poppy was affectionately known as Pop, because he was always on the go and popping up around town. When he became a politician, he once said in an interview that of his five kids, Nancy, my mother, had the likeliest disposition to hold office. As an extrovert, she was prepared to be helpful whether people wanted help or not, and made daily rounds in our town like an ambassador. We spent a lot of time getting in and out of the car. The people on our circuit tended to be Italian or Irish relatives, Roman Catholics and Democrats, or some combination thereof.

We’d bounce between Mary and Rose’s (mother and daughter), Joe and Josephine’s (town funeral director and wife), our mother’s high school friends with kids our ages, or our neighbors: Dottie and Neddie, the Zoras, and the Ziembas. Weekdays we had lunch at our grandmother’s with our aunt Ginny and Lori and Lynn. The women watched soap operas and smoked while we played in the cellar or on the big rock. Almost all the adults smoked, and most of them drank, too.
Chris on the toilet, and Dianne on the floor, reading, circa 1968.
During summer months if anyone had a pond, pool, or place on the lake, we might hit him or her up to cool off and stay for supper. Besides celebrating most holidays with my mother’s family, we hosted and attended birthday parties, graduations, showers, christenings, first Communions, confirmations, weddings, wakes, funerals, sporting events, concerts, and plays. Add to that political rallies, church bazaars, weekly Mass, parades, and our calendar was always full.

When we were at a house where there were no kids, my sister and I tried to score sweets—usually the offerings were hard candies like butterscotch, cinnamon, and root beer barrels. They were mixed together and sold in one bag that should have come with instructions on how to do the Heimlich maneuver.

I was also a big snooper, but I couldn’t do that with Chris who, like my mother, was always more oceanic: noisy, outgoing, open, and on the move. To ditch her with the adults, I’d say I had to go to the bathroom. On my way there, curious to see what people had hidden away and thrilled to be doing something slightly bad, I’d open any available drawers, check closets, and eventually make my way into the bathroom, the only place I could usually lock the door, for some real exploration. But that was the extent of my adventurousness. My motto has mostly been better safe than sorry.

Back home at the red house, I felt more comfortable taking in the view from the porch, but Chris was a real trailblazer, tantalized by the possibility of escaping to freedom. When she was five, she climbed into our mother’s Impala and lifted the parking brake, which sent the car coasting into our backyard. Our mother saw it from the kitchen window and ran out. She said she found Chris sitting on the driver’s side floor, smiling; the car had miraculously stopped before a series of trees. One summer morning my sister got up at 7:00 a.m. while the rest of the family was sleeping. She opened the gate at the top of the stairs, unlocked the front door, and headed outside. Mrs. Masker, who lived around the block, found Chris and brought her home unscathed. My sister was looking for Mrs. Masker’s daughter Charlene, our beloved babysitter. Later that day, our mother screwed hook and eye locks on the outside of both our doors, even though I’d stayed put.

After that, when Chris and I would wake, we’d lie on the floor behind our newly secured doors and whisper to each other through the cracks underneath. I’d push out part of my blanket until it touched the bottom of
her door and she’d clutch it. This created a supple, pacifying bridge between us. Eventually, we’d want to be released, but instead of asking to be let out we slowly inhaled air to make this loud revving noise like a chainsaw being started to annoy our mom so she’d finally set us free.
Chris + Dianne on Halloween, circa 1970.
I recently found an early photograph of Chris and me wearing store-bought Halloween costumes. One of us is dressed as a witch, the other a princess. It took me some time to figure out who was who. Our crinkly plastic masks resembled giant scabs, secured to our faces with the type of elastic that inevitably broke immediately after we'd set out to trick-or-treat. We are the same height, with the same shoes, and wearing matching snowsuits under our costumes. I finally deciphered our identities when I noticed a familiar gesture my sister makes—tilting one hand up with her fingers askew. Alas, Chris is the princess, and I am the witch.

I should have known. My mother's nickname for Chris was “Princess,” and sometimes “Petunia,” but to my mother, I was always “Di,” pronounced “die.” Chris took an early liking to regal nicknames, and as the years went on, she began calling our mother “The Queen” or “Queenie” and our father “The Polish Prince” or “The King.” But Chris has always called me “Sister.” This has seemed both a term of endearment and a way to remind me I have no jurisdiction over her: as siblings, our relationship exists on an even plane. There’s something of that sentiment in my mother’s notation on the back of the photo, which reads simply “C + D.”

During our early years my sister and I were inseparable. Our mother often dressed us alike, and for special occasions we wore handmade, matching dresses she'd sewn. We crafted tents in the family room using a card table and blankets. We made up songs on the swingset and got in trouble for eating the neighbor’s cat food, which we’d thought was cereal. We locked ourselves in the bathroom when the doctor came to give us shots, and we once locked our mom out of our grandparents’ small cottage on the Rhode Island shore. While Chris and I sat on the couch laughing, she was outside in her nightgown without underwear, and our neighbor, a guy she
went to high school with, had to hoist her through an unlocked window. Our mother did not find it very funny.

Chris and I are also joined in the notes our mother kept to track what we ate and how we slept, up until we were three and two years old. She’d write, “C + D: scrambled eggs at 7:20,” “C + D: nap at 2.” Our bathroom habits were not synched, but they were still recorded in detail. As time went on, some of our patterns diverged: “C slept well, D up all night,” or “C ate lunch, D hardly ate.”

Though our mother meticulously recorded our daily activities, she sometimes had selective forgetfulness when it came to me; only the first two pages are filled in my baby book. I know she was busy and exhausted with two babies to care for, and that later, she was probably consumed with worry about Chris’s future and her educational needs. But when I was young, I felt insignificant.

She also compared the two of us. “On your sister’s first day of school,” my mother points out, “she didn't even wave goodbye, just waltzed right in. Not you, though. On your first day of kindergarten, Tracy Katz’s mother and I had to follow your bus while you watched out the back window.” Note how she suggests that I, small and trapped inside of a school bus, was able through the sheer power of my anxiety to force two grown women to drive a car behind me. It’s true I got nervous, so I think it was a sweet thing for her to do, but I felt inadequate when she’d bring it up, especially to other people.

A wonderful respite from family life and a great leveler for the two of us was that Chris and I were in the same Scout troop. We started with Brownies and our leader called the shots. We were encouraged to be smart, strong, and speak up. But Girl Scouts eventually highlighted the difference between our ability to be self-sufficient. During day and night camps, Chris was just fine being away from our mother, but I once became so homesick our mom had to pick me up early. I’m sure she wasn’t pleased to drive the 30 minutes to come get me. In 1973, like most young girls in the country, we’d learned of the tragic abduction of seven-year-old Janice Pockett from Tolland, Connecticut. Since Tolland borders Stafford, our parents were more protective, and we were continuously warned about strangers and safety.
When I was nine, I went to my first sleepover at a fellow Scout’s house, Jeanette, without my sister. As soon as it got dark, my phantom stomach-ache, the one that allowed me the excuse I needed to avoid something, cropped up, and my friend’s mom called my mother to pick me up. I was humiliated, especially because for the following week, my mother kept reinforcing the idea that I was bound to fail when I tried new things, telling anyone who’d listen, “Dianne doesn’t like to be away from her mother.” In fact, I’d slept over other people’s houses with my sister and without my mother and been perfectly fine. What made this sleepover scarier was not having Chris with me.

My mother claims she can’t remember anything positive about what I did or liked as a child, so instead she exaggerates certain details for a laugh. I’ve diagnosed her with Faulty Narrative Syndrome, a condition that makes people distort some stories for so long they can’t remember what really happened. It’s like when you drive down a road that you once got lost on and can’t recollect the wrong way or right way because now they’re both familiar to you.

My mother’s humor can be cutting, but she comes by it honestly. The Scotch-Irish side of our family has a caustic wit and a gift for one-liners. Her uncle Norman emceed at various watering holes so often that it’s mentioned in one of our town’s history books. Instead of answering a question with a legitimate answer, she either asks another question or delivers a punch line as if she imagines herself entertaining an audience. When I’ve called to ask about our toddler years, she’s been cagey.

me: Hey.
mom: What?
me: What were me and Chris like when we were little?
mom: Why?
me: Just wonderin’.
mom: You used to ride on your sister’s back and bite her.
me: Like a turtle?
mom: Yeah, like a turtle.
me: Did I bite her, or try ta bite her.
mom: Ya bit her. You were a biter. Are you taping this?
me: No. You always tell that one story. Did I bite her all the time?
mom: No. (She adds a dramatic pause.) Sometimes ya bit me.

She also likes to point out that I was the “most colicky baby who ever lived.” Chris had colic, too, but recovered in half the time, whereas I’m told I cried for a full six months. Once, after hearing her say this for the umpteenth time, I asked, “What was I like when I stopped crying?”

Her punch line: “By then I hated you.”

In her defense, not knowing how to comfort your infant is brutal for any caregiver. The doctor advised that when I got too loud, she should run the vacuum. I don’t know if that was to soothe me or drown out the sound of my crying. At 26, she had two babies, a husband who worked out of town all week, and though she found support with siblings and friends, they were busy raising their own kids. On top of all that, she and my aunt Barbara tell me I didn’t like to be touched. There are technical terms for this now, like “tactile defensiveness,” but not then. Through trial and error, my mother learned I had to be held facing out, I didn't like the motion of a swing, and I didn't like to be pacified by being cuddled or hugged. That’s how my aunt words it, anyway. My mother says I was “unlovable,” meaning not that I wasn’t worthy of love, but that—especially in contrast to my older sister, who welcomed affection, and to whom my mother was accustomed—I was unable to be “loved” by being held. I couldn’t tolerate the kind of nurturing that was offered. This may have been because I left the hospital at a low birth weight (five pounds), and I assume our issues with bonding started soon thereafter.

As I got older, even when I was sick, she insisted I go to school, which was why I had perfect attendance from first to third grades. But in fourth grade I began showing symptoms of what was eventually diagnosed as Lyme disease and my mother kept notes on everything, brought me to specialists, and fought tirelessly to find out what was wrong. During the many nights where I was in too much pain to sleep, she stayed up, too, continuously checking on me and asking how I was. On school days, I stayed with my grandmother and Aunt Ginny who fed me, gave me my medicine, and cared for me. It was over a month before I recovered.

When I’ve asked Chris what she remembers about us being kids, our conversations are some variation of the following:
Chris: When I was a baby I had fuzzy hair on top of my head.

Me: What do you remember about the two of us?

Chris: You and me are twins. We were in Mom’s belly together.

Me: Oh really, I was with you?

Chris: Yes, Sister. But, I’m still older than you. (She pauses.)

    I used to smoke and fly planes.

Me: (laughing) As a baby? At the same time?

Chris: I never lie.

Though she’s an unreliable witness with a major case of Faulty Narrative Syndrome, I still get a kick out of her inventive version of the past.

During summer breaks from grammar school, Chris and I were part of the town’s recreation program. Our mother made sure they offered a group for my sister and other kids with disabilities, and I was placed with them rather than with my typically developing peers. Looking back I don’t recall if that was because I wanted to be with my sister and her peers, whom I knew better, or because our mother wanted us to stay together.

I do know that around this time came the expectation that I was to shoulder more adult responsibilities and aid my mother by taking care of my sister on a regular basis. “You were always looking out for Chrissie,” an older cousin told me when I asked what she recalls about us from back then. “She was chatty and silly and you were quiet and sad.”

That certainly fits with my memories of my own shyness. I hated when strangers came to our house to visit. I’d either sit on the vacuum, stored in the hall closet, or take shelter to read beneath the cellar stairs. It was a little storage area with a door and a light. It was made of pine and smelled nice. I liked to trail my finger along the amber lines of shiny pitch, sometimes hoping my family would notice me missing and try to find me, sometimes hoping to disappear. It was here I began to discover the kind of stillness that would help render me invisible, as well as the kind of indifference toward others that could make them disappear.

I had a tough time with the way my identity in the family was changing. I’d been my mother’s daughter and my sister’s sister, but I was slowly transforming into my mother’s sister and my sister’s parent. Still, my mother retained plenty of control over us both, as would have been clear to anyone who shared a meal with us. While she no longer kept a written log of
what we ate, she’d begun, like a sportscaster, to replay our daily intake if we asked for a snack before bed: “Ya already had eggs, hot dogs, chips, ice cream, spaghetti, bread, and salad today. Ya really think you need a snack?”

Chris and I had very different body types. Chris was chunkier, so our mother scrutinized what she put in her mouth at home. Wherever else we went, though, Chris circumvented her by requesting treats from others who usually complied. I, on the other hand, was thin, so our mother pushed food at me. I was what they called “picky.” Perhaps this allowed me to have control over one thing in my life.

In first grade the only thing I wanted packed for my school lunch was American cheese and yellow mustard on white bread. Each day, it stewed in the coat closet and absorbed the eau de sour-milk cologne of my metal Jets lunch box. (I’d wanted the one with the picture of Davy Jones, whom I dreamed of marrying in our backyard, but the only department store in town had quickly sold out, so I was stuck with a boy’s lunch box.) While I rejected most food, I loved sweets. I learned the various places my father hid chocolate and raided them when no one was paying attention.

During meals I often snuck Chris food I didn’t want. When our mom left the room for a minute or turned her back at the sink I immediately leaned over and put food on my sister’s plate while miming zip your lip. It didn’t always work. A few milliseconds later Chris might say, “Thank you, Sister!” prompting our mom, in our little dinner theater, to say, “Why is she saying ‘thank you’?” Or Chris might say, “OK, Sister, I won’t say anything,” which our mother followed with, “What is it you won’t be saying anything about, Christine?”

To dissuade us from joining forces, being silly, and causing trouble, our mother always sat between us at the kitchen’s island. I sat on her right and my sister on her left. The separation could only do so much, though, and we found ways to connect and annoy our mother, mostly by copying each other. It started with my sister poking her head around our mom to see what I ate and eat it herself. If I ate broccoli, she ate broccoli. If I swallowed a bite of potato, she swallowed a bite of potato. Once I caught on that Chris was mirroring me, I ate and drank faster and faster until our mom shouted to me, “Stop eating so fast, you’ll choke!” and to Chris, “Stop copying your sister!” But my sister didn’t stop.

My coup de grâce was to pretend to pick up my fork but instead grab my
milk and start drinking. In her hurry to catch up Chris would either dump her milk on the table or spill it on herself. We both loved this routine, but usually—BOOM—our mother would ball her hands into fists that thrust out to give us each a punch in the arm.

I pictured her outstretched arms working like a plus sign, our bodies spelling out the phrase she wrote on the backs of our pictures: C + D. Add us together, and you’d get an integer greater than either of us. But what exactly did we add up to, and what did our togetherness mean for us as individuals? I sometimes longed for an ampersand to connect us instead: C & D. This would have preserved our separate selves, while keeping us close together: Chris and Dianne. Instead, as the years went on, we were altered into another symbol—an obelus, or division sign, ÷: Chris was the top dot, me the lower, and my mother was often the line between us.
Chris, performing with Happy Louie & Julia, circa 1975.