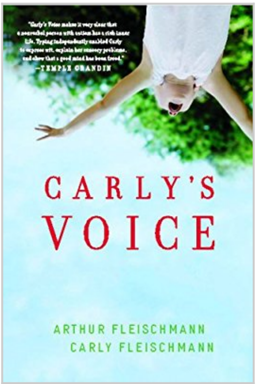

# Carly's Voice: Breaking Through Autism

By Arthur Fleischmann

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While working with her devoted therapists, Carly reached over to their laptop and typed “HELP TEETH HURT,” much to everyone’s astonishment. Although Carly still struggles with all the symptoms of autism, she now has regular, witty, and profound conversations on the computer with her family and her many thousands of supporters online.

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## Editorial Review

Review
"Carly's Voice makes it very clear that a non-verbal person with autism has a rich inner life. Typing independently enabled Carly to express wit, explain her sensory problems, and show that a good mind has been freed." (Temple Grandin)

"I have learned more from Carly about autism than any doctor or 'expert,' and she has helped me understand and connect with my son in ways I couldn't have imagined. Her book takes the autism conversation to new places and disproves the ridiculous notion that non-verbal people with autism don't have feelings and thoughts or are unintelligent. Carly is--for me--autism's fiercest and most valuable advocate." (Holly Robinson Peete, actress, author, and autism advocate)

“Carly's Voice is the wishful slogan of a movement. Autism has spoken, and a new day has dawned. Carly's story is a triumph.” (Richard M. Cohen, author of Strong at the Broken Places and Blindsided)

“In this unsparing but affecting account . . . it’s clear that while most people take the ability to communicate for granted, for Fleischmann it defines her daily struggles and miraculous successes. . . . [An] inspiring story.” (*Publishers Weekly*)

“To read along as [Carly] expresses her feelings in conversations with her father is almost as stunning as when she writes of life inside her autistic head. . . . Both heart-wrenching and deeply inspiring.” (*Kirkus Reviews*)

“Throughout Arthur Fleischmann’s exceptional memoir about his and wife Tammy’s experience raising a child with severe autism, it is the plaintive “voice” of the wordless-from-birth Carly that resonates. . . . It is Carly’s chapter, written in her words, and her charm that set this memoir apart.” (*Booklist (starred review)*)

“A well-written story of one family’s struggle, perseverance, and triumph in helping a child with autism find her voice. This book will benefit people with autism, their families, and all who interact with them.” (*Library Journal*)

“[Carly’s] explanation of what it feels like—emotionally and physically—to have autism is eye-opening. Quite frankly, I think [her] chapter should be required reading for our society, especially as we head into Autism Awareness Month.” (*Parents.com*)

“Witty, sarcastic, and heartfelt, Carly’s words shine with personality and intellect, her strength and determination adding sparkle and hope.” (*New York Journal of Books*)

About the Author
**Arthur Fleischmann** lives with his wife, Tammy Starr, and their three children, Matthew, Taryn, and Carly, in Toronto, Canada, where he is partner and president of john st. advertising.

**Carly Fleischmann** lives in Toronto, Canada, and attends a mainstream high school where she is enrolled in gifted classes. She corresponds with her thousands of friends and followers via Twitter and Facebook. Visit her at CarlysVoice.com.

Carly’s Voice

## 1

## In the Eye of the Storm

A news reporter once asked me to describe our a-ha moment with Carly. He wanted to understand that blinding flash of insight we had had about our daughter. I thought for a moment before replying, “There never has been a moment like that. Carly has always just been Carly.”

From the moment our daughters were born on a gray morning in January 1995, both my wife and I knew which twin—Twin A or Twin B—was going to grow up to live the life of Carly, and which would become Taryn. Call it intuition or cosmic intervention, but one baby just was a Carly.

After the unsettled time around the birth of our son four and a half years earlier, we were elated to close the book on trauma and start a new life with our enlarged family. Matthew had been born during the grieving period for Tammy’s mother, who had died suddenly just months before his birth.

Having the twins had not come easily. Creating life was not an issue for Tammy; sustaining it had been. After three miscarriages in the years after Matthew was born, we were about to break the curse. We looked forward to a fresh start. Quid pro quo; we were owed that much.

“How many bedrooms do you have?” Tammy’s obstetrician-gynecologist had asked her cryptically five months earlier, during the summer of 1994.

“Three,” Tammy replied.

“You might want to consider four,” Dr. Amonkwa said.

It seemed that the Clomid, progesterone, and aspirin that he had prescribed had broken the cycle of lost babies and parental despair. Rather than one child, Tammy was pregnant with twins. Other doctors had told us that perhaps more children were not meant to be. But we, and in particular Tammy, seldom took “perhaps not” at face value.

After careful monitoring for the rest of the nine months, Tammy gave birth to our daughters. We considered naming them after the drugs that made their successful birth possible, but Clomid and Progesterone Fleischmann would have been cruel.

Our older twin and middle child arrived at 7:38 a.m., and her little sister, Taryn, fourteen minutes later. Carly had been the feisty one in utero, clamoring to get here. But once she arrived, she seemed to take a look around and say, “Oh, wrong place.” This world would never be in step with our little girl. Within weeks of her birth, Carly took on a startled and cranky look, one that matched her demeanor.

Taryn was peaceful and elegant with a cap of dark hair and a quizzical expression. But Carly arrived blotchy and patchy and looking surprised. From the prenatal medical records, there was little to suggest that the fraternal twins would have such different fates. Tammy’s medical chart indicated that the delivery of the girls was “spontaneous, vaginal, and uncomplicated,” much like the act of their creation had been. After a week in the hospital, we bundled our tiny new-potato-like parcels into furry winter baby buntings and brought them home to our modest Toronto house.

The next six months were a bleary, sleep-deprived period of normalcy. As normal as a household can be with three children under five, two of whom eat every three hours, twenty-four hours a day. Tammy and I would plod up the steep, narrow staircase to our bedroom around 9:00 p.m., lugging two babies and six mini-bottles of formula. Frighteningly, all six portions would be consumed before 5:00 a.m. the next morning, each feeding followed by the requisite diaper change.

Tired as I felt, I couldn’t fail to smile at the two little swaddled lumps. Carly and Taryn slept in a large woven basket that we placed atop a low dresser that Tammy had been lugging through life since college. It was stained a puzzling shade of green and had more sentimental than aesthetic value. Now tucked into an alcove in our bedroom, it served as a pedestal on which our daughters started their lives.

The two girls had spent nine months pressed together in Tammy’s womb and felt completely natural being tucked in tightly, snuggled closely. We made a conscious effort from the start to give them unique identities, refraining from dressing them the same or referring to them as “the twins,” but rather as Carly and Taryn. Yet, they were two halves of the same whole and would lie together, reaching out and touching each other, practically hugging. How were we to know that one day they would grow to be like the front and back cover of a book—matching opposites—with so much separating them?

Since dinner parties were out of the question (not that they happened often before the girls’ arrival), we covered our dining room table with a large pad and plastic tablecloth for changing the babies when downstairs. Tammy’s friend Sue would come over on Sunday afternoons and help us with laundry. While Tammy simultaneously fed the two babies, Sue and I would cook as much food as we could squeeze into our freezer for the week ahead. The first months were a blur of laundry, poo, spit-up, quiche, and lasagna. But Tammy was happy to have a family after the false starts and dying hopes. I have scores of photographs of the early days, each of us taking turns holding both babies. We both seem to have a tired but amazed expression, as if to say, “How’d this happen?”

Life took on a chaotic rhythm that was made manageable by the arrival of our nanny, Mari. Mari had recently moved from St. Lucia to join her sisters and cousins; one sister worked as a nanny for a friend of ours. She took to our daughters immediately, a broad, open smile spreading across her usually serious face whenever she saw the two girls. Although a very quiet person, Mari exuded confidence in running our household—a thankless task we were more than happy to relinquish. For the next twelve years she would buttress our family and steadfastly help care for all three of our children and home. Tammy and Mari divided the never-ending tasks of Matthew’s school and after-school activities and the seemingly endless work required to keep Carly and Taryn fed and clean. Tammy and I took a divide-and-conquer approach from the start, something that would stand us in good stead in the years to come.

My career had me at the office by 8:00 a.m. and seldom home before 7:00 p.m. Nevertheless, after work I did my best to focus on Matthew—to be sure he wasn’t left out. We had been warned that boys in particular could get regressive when new babies come into the house. I recall my brother more as a tormentor when he was nine or ten. He once tried to feed me cat food and put pepper in my sister’s chocolate pudding. On other occasions, he would hide under my bed or in the closet at night until the lights were out, then jump out and scream. Ghouls really do exist, at least until they become teenagers. Eventually, even little boys outgrow their wickedness.

Not knowing what to expect, I assumed Matthew might continue in the family tradition since he had his rambunctious tendencies. A year or two before the girls were born, we had bought a book titled Raising Your Spirited Child to help us understand why even the smallest thing, like an itchy tag at the neck of his shirt, could set off a full-blown tantrum. He was a rigid kid who vacillated between playful sweetness and the terrible twos that had overstayed their welcome.

While Mari and Tammy bathed the girls, I would eat dinner with Matthew. Then, in the warming spring evenings, I would take him to the park. As we walked, I often reflected on how Matthew’s infancy was also anything but ordinary.

Always a snorty eater, in the fall of 1990 when Matthew was eight months old, we had to rush him to the emergency room, barely able to breathe. After several days in the hospital while the doctors ran tests, we were told Matthew had been born with a double aortic arch. The vessels carrying blood to and from his heart were wrapped around his trachea and windpipe, literally strangling him like jungle vines choking a tree.

But Matthew was a trooper and rebounded from surgery quickly. Five years later, Matthew loved to hear how he had been a brave patient, how he was giggling and laughing within days of his operation. He wore his scar as a badge of honor. “You have no trouble eating now,” I joked with him. “Remember the time when you were two and Mom and I caught you taking an ear of corn out of the garbage after dinner?” Tammy and I had been washing dishes, and, upon hearing Matthew making noises of gastronomical bliss, found him smiling up at us as he finished an ear of corn that had been scraped from a plate into the garbage.

By late spring, the girls were sleeping through the night; Matthew was on a schedule; and Tammy and I even got an hour or two of quiet time before bed. We felt like we had gotten off the dirt road and onto the open highway. We traded a sedan for a minivan and ventured out on day trips and visits to friends, always lugging the girls, an oversized twin stroller, a huge diaper bag, and our rambunctious five-year-old son who ran circles around us making sounds like the Indy 500.

Before their first birthday, however, we began to see Carly and Taryn heading in different directions. Our first challenges with Carly were innocuous enough. Tubes in her ears to relieve the heavy fluid buildup one month. A few tests with audiologists to be sure the infections hadn’t compromised her hearing the next. Tammy and I could handle this level of intervention. Lots of kids had tubes put in their ears. It was as common as diaper rash. Just by looking at her, however, we knew that Carly had deeper issues than goopy ear canals.

While Taryn’s skin had smoothed into creamy baby softness, Carly’s often had a ruddy, chapped look. Taryn’s eyes seemed to giggle almost from birth, while Carly often wore a dozy gaze. And while Taryn was making headway at crawling, pulling herself up, and achieving all the other milestones of a toddler, Carly languished on her back. The biggest difference between the girls, however, was their personality. Taryn was happy and peaceful; Carly cried incessantly, earning her the nickname Cryly.

Our pediatrician did not seem particularly alarmed, but after the experience we had had with Matthew, Tammy and I were on full alert. We were referred to a physiotherapist at the Hospital for Sick Children, the first of what would become a legion of specialists. When it was clear that one appointment per week would not get Carly moving, Tammy enrolled her in a private clinic. Three times a week Tammy brought Carly to physical therapy, where they would tediously coax Carly from lying to sitting, and from sitting to butt-shuffling across the floor.

Excerpt from progress report, Play and Learn Integrated Nursery Program, January 4, 1996:

J. Spitz, Coordinator

## SUMMARY AND RECOMMENDATIONS

At 10 months of age Carly has shown some delays in her language, gross motor, auditory attention and memory, self-help and socialization skills. Frequent ear infections with fluid in the middle ear may certainly have impacted her language and auditory attention and memory skills. She appears to have some generalized low tone which may be impacting upon her gross motor skills at this time. Therapy input seems to be appropriately managed through the two therapists seeing Carly at this time. This gives Carly intensive focus on motor development at this time. Carly and her mother have begun the weekly parent and child program at Play and Learn. Through this program we can target specific skills through a play approach. As well, home visits can commence at the family’s convenience to provide other suggestions of activities that will enhance Carly’s development. She will be reassessed in six months.

Just after Taryn’s and Carly’s first birthday, we had to acknowledge that Tammy’s obstetrician had been right. We needed a bigger house. Our dining room, which hadn’t been used for eating since the girls arrived, was filled with toys and scooters. Our kitchen, barely large enough to be described as “eat-in,” required that we eat dinner in shifts. And the two small bathrooms were always a traffic jam.

With three children instead of the planned two, we scrapped the idea of sending Matthew to private school and in the winter of 1996 found a house in a leafy section of the city near excellent public schools, parks, and stores. If not exactly a dream home, given our budget (which we overshot), it was more house than we had hoped for, and compared with our cramped quarters, it was a mansion. Four bedrooms, a den on the main floor, and a finished basement for a playroom. No more tripping over fire trucks and sit-on turtles with wheels. “They’ll carry me out of here in a body bag,” I told Tammy.

This was to be our house for life. I sought a measure of serenity in a home to counterbalance my rapid-fire job and rough-and-tumble family. Despite the awareness that Carly and Taryn were developing on diverging paths, I was confident we were starting something new and exciting. I had recently changed jobs, joining a hot new ad agency that had recently opened in Toronto. I was given a significant role in running a large portion of the agency’s flagship beer account. With my newly enlarged family and a house in a great neighborhood with good schools, I was feeling pretty pleased with myself.

But as the professional side of my life took off, my home life was about to slip into quicksand. Tammy was anxious about the growing chasm between the two girls. “Something’s off,” she said. I chalked it up to her vigilant nature and refused to put it on my “to worry about” list. Nevertheless, my wife began exploring play groups that would be ideally suited to both girls. Taryn needed the stimulation to match her extroverted personality; Carly needed it to pull her out of her sluggishness. For the next year, the months between the girls’ first and second birthdays, they went to what was clinically termed an “integrated early intervention program.” For several hours, several days a week the girls would go to a center resembling a cross between a kindergarten room and a kid’s birthday party. There they would encourage Carly to use her hands, paint, and play like the “integrated kids”—those more like Taryn. There are still pictures of Carly, smiling, covered in finger paint festooning a wall in our basement. But these playful pictures captured only moments in time. As soon as Carly was home, she would sit on the floor of our den rocking back and forth, humming to herself, and ignoring the world around her. Play was not something that came naturally to our daughter.

One of the instructors at Carly’s program told us, “You have to stay in her face.” Specialized workers, originally paid for by insurance and then later out of our own wallet when benefits ran out, would arrive at the house with jangly toys and oversized Raggedy Ann dolls. For hours they would sit on the floor of our den or the playroom with an exaggerated cheerfulness, encouraging Carly to follow instructions, take items from one hand and pass it to another, and play like other two-year-olds. Carly mainly stared up at them with a look that was a mixture of wonder and boredom. Taryn, on the other hand, was already off to play dates with friends.

After mornings at preschool, Tammy spent the afternoons making the rounds at medical facilities and hospitals. Sometimes I would take time off work to join her. The next four years would feel like an incarceration in a house of mirrors. One doctor unable to explain Carly’s lack of progress would send us on to another, who then pointed us in another direction.

Step 1: Wait in beige-and-gray waiting room filled with toys you don’t want child to touch for fear of infection by flesh-eating disease. Little worry for us, however, as Carly ignored pretty much everything. Depending on the type of doctor (neurologist, audiologist, geneticist, developmental pediatrician), exchange sympathetic looks with other parents of kids who appear equally (but seldom as severely) out of step with the world as Carly. Note: If at doctor such as ear, nose, and throat, avoid sidelong glances of other parents who stare at Carly secretly thanking God their child is playing with flesh-eating-diseased-Playskool-firehouse while Carly sits on the floor and rocks back and forth.

Step 2: Admission to claustrophobic examining room with the assurance that doctor will be along shortly (what’s the medical definition of shortly?) and the taking of medical history by the resident or intern (“Can’t you just read the notes from the previous eight doctors? You tell me what’s wrong.”).

Step 3: Repeat the medical history when the specialist finally arrives just as Carly is completely losing it, screaming at the top of her lungs and attempting to fling herself from the stroller, tethered by a waist strap; stare up at the pensive, twisted face of the doctor as he/she reads through a four-inch-thick chart.

Step 4: The perfunctory physical examination of eyes, ears, pelvis, back, limbs, and joints while Carly writhes and screams, making said examination even more perfunctory. Think to self, “What can poking at our daughter uncover that the millions of dollars in scans and blood tests failed to reveal?” A physical exam cannot possibly give us any insight into what’s wrong with Carly.

Step 5: The raised eyebrow and sympathetic arm touch by doctor as we’re sent on our way to see another special specialist. On occasion, stop to pick up requisition for additional blood work or scans of head or random body part.

Step 6: Repeat and repeat and repeat until numb.

The momentum of appointments, play groups, and therapy was accelerating at an alarming rate. The notes, papers, and schedules of doctors’ consultations taped to our refrigerator were elbowing out Matthew’s and Taryn’s artwork and magnetic letters. There were weeks where Tammy had at least one doctor or therapist’s appointment every day. We referred to these years as the Fix Carly Years. Both Tammy and I have backgrounds in business and marketing; we are career problem solvers. We hunched our shoulders to the gristmill and pushed. In particular, Tammy took this on as a mission. In the evenings, she would recount the conclusions from an appointment I had missed, though I confess many of the details washed over me. Months melted into a slurry, with little to show for it. On paper, anyway, Carly was perfectly healthy.

Carly became known as “the enigma of the Hospital for Sick Children” by the team of doctors who had followed her. She had been assigned the label GDD (global developmental delay) because she was missing most of her developmental milestones such as walking, talking, playing, and following basic instructions.

Later they added pervasively developmentally delayed—a broad term for a spectrum of conditions such as autism because of her lack of eye contact, social engagement, and speech. But there was no underlying cause for these conditions. Carly’s lack of speech development was particularly confounding. It would be several years before her inability to make more than garbled sounds would be diagnosed as apraxia—a motor-planning deficiency in which the muscles in her mouth failed to obey the directions from her brain. We could find no ailment to cure or person to blame for Carly being so Carly. Our naïveté about what lay ahead was a blessing; we refused to be discouraged. Delayed had an optimistic ring. I reasoned that planes and trains that were delayed would eventually arrive. In fact, many of the doctors’ reports told us that they expected gains. Her pediatrician noted that with Carly, it was like being on a ladder: She would move up, but we just didn’t know to where.

It took months of intensive MEDEK, a particularly draconian form of physiotherapy, to coax Carly into walking on her own, which she would finally do just after her second birthday. In addition to therapy appointments at a local clinic, therapists came to the house to teach Carly how to hold a cup, move items from one hand to another, and work on her fine motor skills—all the things most children intuitively learn. When a therapist wasn’t persuading Carly into a standing position or encouraging her to put pegs in holes, stack blocks, or thread a spool with string, Mari was. While Taryn played, Carly worked; she worked harder than most adults.

At times, the girls were not so very different. On occasion, Carly could be all smiles and giggles. The sisters would roll around like oversized puppies on their bedroom floor, Taryn hugging her sister and saying, “Oh Carly, oh Carly,” in that one-way conversation we’d all learned to have with her. Carly giggled from the attention. From a very young age, Taryn reacted to her sister with good humor and empathy. I sat on the den floor and would take turns bouncing them on my knees, singing the children’s song “The Grand Old Duke of York.” But while Taryn would gleefully yell, “More, more Grappa Dupa Yorp” when I finished the rousing chorus, Carly would burst into tears until I started up again. “Again for Carly,” Taryn would say, providing her sister’s voice. Taryn was protective of her sister, guarding Carly as if she were a prized possession. Only on rare occasions when Carly would grab food or a toy away did Taryn scold her with a furrowed brow.

Often, while Taryn would play with her Barbies, Polly Pockets, or coloring books, Carly would sit nearby holding yet another developmental discovery toy we had purchased in the hopes of engaging her. She would not play, per se, but rather turn the toy over as if to check its country of origin and scratch at the imprinted bottom surface. Her nails would trace over the embossed words like she was reading Braille, but her eyes told me she was elsewhere. Often she would put her tiny index finger into the screw holes that held the brightly colored plastic pieces together.

When not holding a toy, Carly would stare at her hands and wriggle her fingers as if she were meeting them for the first time. “Carly’s doing fingie,” Matthew would say. I would look on, encouraging her to press the green button to illuminate the green light, or to stack the colored cups. I could not enter her world, whatever world it was, and fruitlessly called her into mine.

Try as we did to encourage Carly to entertain herself, even for a few minutes, the only acts she would spontaneously engage in were rocking and banging. Pressing her heels deep into the mattress of her bed or the cushions of her favorite overstuffed chair in the den, Carly would lift herself to near-standing and then slam back with full force. All the while, she would drone ahhhh ahhhh ahhhh—as soothing to us as nails on a chalkboard—and stare into space. If uninterrupted, her methodical, vertebrae-shattering ritual could go on for hours. Despite best efforts to redirect her or at least cushion the blows, she ultimately wore holes in the chair and broke her solid oak bed so often that it eventually required steel-reinforcing bars. This much we knew: Carly had strong core muscles. If nothing else, she likely would never have a bad back.

Excerpt from psychologist’s assessment, February 2, 1997:

Dr. M. Mary Karas

## DIAGNOSTIC IMPRESSIONS

Carly is only 25 months old. Yet with increasing awareness of the characteristics of the PDDs, one can offer a provisional diagnosis consistent with her behavior profile. Although she presents with the main characteristics of the developmental delay, she also presents many features of the PDDs. She is resisting change, is affectively isolated and has no functional communication other than through elementary gestures. She is quite unaware of danger and seems to have a vague awareness of the characteristics of the people around her . . .

## SUMMARY

The psychological testing revealed that Carly is delayed in a number of developmental areas consistent with a diagnosis of PDD since she seems to represent with greater delay in the area of language than intellectual abilities. Carly’s developmental delay is at present the major consideration, but her parents’ and caregivers’ awareness of her meeting many of the criteria for Autistic Disorder should also be of relevance to programming efforts for her. The fact that she grows up with a highly competent co-twin make her delays more evident to her parents and may have a more adverse effect on them than had she been a singleton. On the other hand, her sister should provide a role model for her to stimulate as well as play companion. The fact that Carly enjoys her play and games with her sister reflects this benevolent influence of Taryn on Carly.

Fifteen years later I looked through the color-coded medical files and remembered how much I had forgotten. True, Tammy had maintained the frontline role of investigator in attempting to unearth the causes of our daughter’s issues; I worked to pay for that which insurance or socialized medicine would not. But I was not completely absent. Doctors’ clinical notes refer to my presence at appointments I have long since purged from my memory. I have little recollection of the consultations with geneticists, neurologists, audiologists, dieticians, physical therapists, occupational therapists, developmental pediatricians, and psychologists that would become a full-time occupation for Tammy. And after all that, after years of blood tests, skin biopsies, metabolic studies, MRIs, evoked potentials, hearing tests, and God recalls what else, we knew only this: Carly was, as her developmental pediatrician stated in her notes, complicated.

Scanning the doctors’ notes reminded me of all the things that Carly wasn’t. Most parents have a long list of comical stories from their children’s early years. Once I lay sprawled across our bed, grabbing five minutes of quiet while the twins napped. Just as I dozed off, Matthew pounded through the bedroom like Napoleon invading Italy, chanting “stinky farty butt, stinky farty butt,” and knocked over a framed photograph balanced on the nightstand. When he noticed what he’d done, he contritely stammered, “I’ll fish stick,” meaning to say “fix it.”

Taryn made us laugh with her independence and vivacity. Taking toys out of the closet, she would settle on the floor at our feet and happily play for hours. She always maintained a sense of humor where her sister was concerned. Once Carly was lying naked on our bed after a bath; perhaps she was three or four. Taryn picked up one of Tammy’s credit cards that was on the nightstand and pretended to swipe it in the crevice between Carly’s buttocks, announcing, “I’ll pay with credit.” She and Tammy laughed so hard tears streamed down their cheeks.

A few minutes later, Taryn came back into our room and dropped her pajama pants to reveal a Tootsie Roll poking out from her bottom. She squealed, “I have a fudgy butt!” before falling to the floor in gales of laughter. Perhaps I should have been concerned about my children’s scatological preoccupation, but it provided such comic relief that we encouraged it.

Even Taryn’s sassiness had an innocent sweetness to it. She once called her nursery school teacher missy. “My name is Miss Whittington,” the young woman corrected her. “Okay, Missy Miss Whittington,” Taryn said with a giggle. Even at three she had a comic’s sense of timing.

But I cannot think of any such memories of Carly.

The pages that document the first years of Carly’s life are an inventory of inabilities. “Working with Carly was hard,” noted her developmental pediatrician upon our first consult. “I got her to sit at the table and take objects I offered to her, but she was unable to stack cubes or put pegs in a pegboard. She did not respond to any language cues. I heard some consonant babble, but no isolated words.” Even a year later, after hours of intervention, Dr. Stephensen, a developmental pediatrician we saw regularly, noted that “I still find Carly a bit of an enigma, but one cannot deny that she has gotten a thorough workup with so many consultants involved.”

Even when Carly did acquire skills, they were often used in ways that reminded me that she was distinct from her brother and sister. Once she learned to walk, she immediately began to run—generally headlong into dangerous situations like a busy street. Once she found the joy in grabbing objects, she began flinging them—a plate of food or a cup of juice. I came to appreciate Mari more and more. After dinner, she would sweep and mop up the pounds of food Carly had flung (had she actually eaten anything?) and take the girls out for a walk to the park.

For the hour they were out, the house was reasonably quiet. Matthew’s best friend lived across the street, so the two were inseparable after school. Tammy would be at her desk plodding through the reams of forms the government creates to discourage those of us in need of help from applying for it. And I could sit quietly, read the paper, and eat in silence for thirty minutes and ready myself for when Mari left for the night and Carly was gearing up for round two. Not exactly a family meal, but we were making the best of our distorted reality.

Perhaps we’ve never felt an a-ha moment with Carly because her progress was overshadowed by her challenges. She finally learned to walk and, in a fashion, feed herself. She could utter a few bleary words such as mama and cackah, meaning cracker, or ooce for juice. Even these approximations for language would soon evaporate like steam. By four years old, she was not toilet trained and would awake in the middle of the night and remain volcanic for hours. No sooner up, she would strip off her pajamas (a skill in itself, her developmental pediatrician reminded us), rip off her diaper, and jump about her room barking ahhhh ahhhh ahhhh. And then rock. Always the incessant rocking. The rocking became the manifestation of everything I hated about Carly’s condition. It was irritating, destructive, and unstoppable. “Ssshhhhh,” I would say, but it came out more like, “Stop, God damn it.” In some ways it was best that Carly couldn’t speak; my expletives were often free-flowing.

Taryn, who shared the room with Carly, somehow slept through it. Either that or she had learned the first lesson of growing up as the sibling of a disabled child: Lay low. Tammy’s and my exhaustion and frustration from the Sisyphean task of remaking the bed, reclothing Carly, and tucking her in left us in a perpetual short-tempered state.

Tammy spent hours searching for someone who could help dissipate the hurricane that was our daughter. We couldn’t find anyone up to the task, much less a cure. What simple solution could there be to stop a thirty-pound child from hurtling her body full force against a wall? We learned to improvise and tackle bits and pieces at a time. One night I came in to kiss Carly good night and found Mari had put Carly in a tight-fitting Lycra bathing suit over her diaper. “She has trouble taking it off and she seems to like it,” Mari explained. We had read that some kids like Carly were comforted by the sensation of snugness. Besides, if she couldn’t remove the bathing suit, she couldn’t remove the diaper. It was a novel solution that we used until Carly became fully toilet trained—a skill she finally mastered when she turned five. At least foraging in the dark for her pull-ups and her pajamas was a thing of the past. Getting her to sleep through the night would be something that would take another seven years, however.

In addition to being diagnosed with severe autism and oral apraxia by her developmental pediatrician, Carly had been identified as having moderate to severe developmental delay at the age of two. It was a broad and general expression that has replaced the abhorrent term retarded and is used when doctors can’t identify any specific condition. “Carly has no specific etiology,” is how they put it. Several years later, I Googled etiology. I learned that it was of Greek origin and meant “the study of why things occur or the reasons why things exist.” Greeks used myths to explain phenomena they couldn’t rationalize. For all the answers we’d gotten as to why Carly was as she was, a myth would have been as useful.

I didn’t blame the doctors for their lack of specificity. How could I? Carly couldn’t engage in many of the diagnostic tests they tried. She didn’t follow multistep instructions or tasks nor could she speak to explain what was going on inside her body. On occasion she cooed when held and cuddled by Tammy and me, and often giggled and laughed with her sister. Most of the time she was content to be adrift in her own world, sitting on the periphery of ours.

As we dragged her from doctor to clinic to lab and back again, day after day, it occurred to us perhaps we were merely trying to label and identify her. How many more needle pricks would we make her endure? Sleepless nights with electroencephalogram leads attached to her little sweaty head? Evoked potential, hearing, and sight exams? Skin and muscle biopsies? The repetitive narrative of providing oral history to each subsequent doctor, nurse, and resident was enough to make us want to call it quits. Through her early childhood, we had learned nothing that was helping her come back to us, nothing that made her play with other children or even play meaningfully by herself, nothing that would help her noisy mouth form intelligible words. We had diagnoses, but little insight into what could be done to help Carly escape the whirlpool.

We were beginning to feel that enough was enough and decided there would be no more physical suffering on account of science. “If it’s just information for information’s sake and no cure will come from it, then it’s time to stop,” Tammy said to me one evening, her body slumped on the couch, defeat on her tear-streaked face. We no longer held out hope that we would discover a specific part of Carly that was broken and could be easily fixed. Global developmental delay, pervasive developmental delay, autism, oral-motor apraxia—all conditions, but none of them specific ailments. Had she had cancer, we’d have known what to do. Had she incurred brain damage or had a stroke, we would understand her condition. But Carly’s affliction was like a blob of mercury: visible and dense and real, but try to grab it and it jumped from our grasp.

Despite what doctors described in her medical records as “valiant efforts by her caring and deeply committed parents,” we would never receive an a-ha moment, much as we craved one. One dead-end street led to another. Somehow, life had to move on. Our other kids were growing and developing. We were running out of referrals and recommendations. And while our medical system is public in Canada, many of our therapies and consults were beyond coverage and had pushed our credit line to the brink. “I feel like there’s a button in her brain we just need to switch on," Tammy said. But that button would remain out of sight, out of reach. In our hearts, we had hoped to find a magic pill that would turn Carly into someone else; someone who could speak, play, and be with us. But that folly had to come to an end. It's not that we would give up on our daughter, but it was time to stop asking why, and start asking now what?

Excerpt from clinical genetics report, October 12, 1997:

Dr. D. Shaet, Division of Clinical Genetics

Developmental milestones are delayed but have improved . . . she does not like laying on her stomach and to move she shuffles on her buttocks. Carly's fine motor skills are delayed but she acquitted many milestones during the last year. She improved her pincer grasp but does not like to touch objects and does not pile blocks. She makes no attempts to put a puzzle together and does not scribble.

Regarding language, she has difficulties both in receptive and expressive language . . . she does not follow more than a one-step command. Carly interacts with her sister frequently, but not other children. . . .

The investigations done so far have failed to reveal any specific diagnosis. I explained to the parents that I doubt if we will be able to further delineate her condition. However, we wish to continue following her every 2 years and would like to be updated of her growth, development and of any medical/neurological investigation done . . .

Sincerely,
D. Shaet, MD, FABMG, FCCMG, FRCPC
Division of Clinical Genetics
CC: file, Dr. I. Tine (Neurology), Dr. D. Stephensen
(Developmental Pediatrics), Dr. J. Kobayashi (Neurology),
Dr. M. Goldstein (Pediatrician)

## A Recurring Dream

I am dreaming a dream I've had many times since Carly was born. The two of us are sitting in the kitchen. Or maybe it's the den. We are talking. Carly is talking. She's teasing me about something.

"How do you like my haircut?" I ask her.

"It looks like your head got caught in a food processor," she deadpans.

I wake up laughing out loud.

Then I roll over on my side and cry.

## Users Review

### From reader reviews:

**Lola Taylor:**

This Carly's Voice: Breaking Through Autism book is not ordinary book, you have it then the world is in your hands. The benefit you receive by reading this book is definitely information inside this e-book incredible fresh, you will get details which is getting deeper an individual read a lot of information you will get. That Carly's Voice: Breaking Through Autism without we understand teach the one who looking at it become critical in contemplating and analyzing. Don't become worry Carly's Voice: Breaking Through Autism can bring when you are and not make your handbag space or bookshelves' turn into full because you can have it within your lovely laptop even telephone. This Carly's Voice: Breaking Through Autism having great arrangement in word as well as layout, so you will not experience uninterested in reading.

**Thomas Woods:**

In this time globalization it is important to someone to obtain information. The information will make anyone to understand the condition of the world. The health of the world makes the information better to share. You can find a lot of personal references to get information example: internet, paper, book, and soon. You can observe that now, a lot of publisher in which print many kinds of book. Often the book that recommended to your account is Carly's Voice: Breaking Through Autism this e-book consist a lot of the information on the condition of this world now. This kind of book was represented how do the world has grown up. The language styles that writer value to explain it is easy to understand. The writer made some investigation when he makes this book. That is why this book suited all of you.

**John Davis:**

Within this era which is the greater man or woman or who has ability to do something more are more special than other. Do you want to become one among it? It is just simple method to have that. What you have to do is just spending your time almost no but quite enough to possess a look at some books. Among the books in the top record in your reading list is Carly's Voice: Breaking Through Autism. This book which is qualified as The Hungry Slopes can get you closer in getting precious person. By looking right up and review this reserve you can get many advantages.

**Louis Ono:**

Many people said that they feel uninterested when they reading a publication. They are directly felt it when they get a half parts of the book. You can choose the book Carly's Voice: Breaking Through Autism to make your own reading is interesting. Your current skill of reading proficiency is developing when you such as reading. Try to choose easy book to make you enjoy to study it and mingle the feeling about book and reading through especially. It is to be initially opinion for you to like to open a book and go through it. Beside that the reserve Carly's Voice: Breaking Through Autism can to be a newly purchased friend when you're experience alone and confuse in doing what must you're doing of that time.

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