

The
Able Life
of
Cody Jane

Still Celebrating

MARLY CORNELL



LIGHTLIGHT PUBLICATIONS

Minneapolis, Minnesota

Copyright © 2011 Marly Cornell
All rights reserved.



LIGHTLIGHT PUBLICATIONS
Minneapolis, Minnesota
LightaLightPublications.com

Cover design by Bookwrights
Cover photos by Dennis Ahlburg
Interior by Dorie McClelland

Some names have been changed to protect privacy.

Scripture quotations from *The Living Bible*. Wheaton: Tyndale House, 1980,
c1971 by Tyndale House Publishers, Inc. Used by permission.
All rights reserved.

ISBN 978-0-9831777-0-8
Library of Congress Control Number: 2010919218

Printed in the United States of America

To all those living on the ragged edge

Contents

Foreword by Steven Haines, MD *xi*

Foreword by Cindy Brownstein *xii*

Introduction *1*

- 1 The Importance of Dogs and Neurosurgeons *3*
- 2 Toddling *16*
- 3 Big House, Big Wheels, Big Surgery *21*
- 4 Questions *29*
- 5 Time for a Miracle *38*
- 6 We Are Family *47*
- 7 Oz to Minnesota *58*
- 8 That's Incredible *67*
- 9 Mainstream Fusion *75*
- 10 Beaches *92*
- 11 Typical? *102*
- 12 Days and Nights *109*
- 13 Eyes and Hockey *118*
- 14 Synchronized Miracles *125*
- 15 Good News *133*
- 16 Blue, Sex, and Action *142*
- 17 The Storm Before the Calm *153*
- 18 Thanks *163*

19	Individuation	171
20	Change	178
21	Moving	188
22	Dating	197
23	Blooming	207
24	Meeting John	219
25	Breathtaking	229
26	Cousins	242
27	Sweet Conversations	254
28	Partners for Life	264
29	Side Effects	273
30	Fear and Faith	281
31	One Week	291
32	Starburst	305

Epilogue	311
Acknowledgments	313
About the Author	314
Glossary	315

*For he orders his angels to protect you wherever you go.
They will steady you with their hands to keep you
from stumbling against the rocks on the trail.*

Psalm 91:11–12
The Living Bible

Foreword

When I began training in neurosurgery the aggressive treatment of babies born with myelomeningocele was still a relatively new idea. Prominent pediatricians and neurosurgeons still had serious discussions about the ethics of treating these children, and experience with adults with myelomeningocele and hydrocephalus was limited. If they had known Cody Jane Ahlburg, the discussion would have been very different.

Cody filled any room she was in. There was no doubt who was in charge. She was smart enough to take control of her life, insist on the care that she needed, and wise enough to accept the advice of those who could provide the specialized care she required. She was, indeed, unforgettable.

Her story is not just one of courage, humor, and refusal to be defeated by serious medical disorders, but also of the multiple medical problems that ultimately ended her life. The condition we call spina bifida affects more than just the spine. The nervous system of a person with myelomeningocele has many abnormalities that can cause difficulty at different times in life. With aggressive treatment our patients have grown up with us, and our experience with the many different manifestations of nervous system dysfunction that adults with spina bifida may encounter is rapidly increasing. The accumulation of problems over time carries significant risks and may ultimately shorten life.

Each of us has limitations that we wish we did not have. If we could face them with the same degree of acceptance, combined with refusal to let them impose unnecessary limitations, that Cody demonstrated, we would live richer and fuller lives, no matter how long we lived them.

Stephen Haines, MD
Minneapolis, Minnesota

Stephen J. Haines, MD is the Lyle A. French Chair and the professor and head of the Department of Neurosurgery at the University of Minnesota.

Foreword

Who among us has not faced a barrier that seemed insurmountable? In a culture where we are all too often labeled by what we *cannot* accomplish rather than by what we can do, *The Able Life of Cody Jane* serves as a reminder that life is simply too short to be defined by others' misperceptions of our abilities.

During a decade of service to the spina bifida community, I've had the pleasure of meeting thousands of seemingly ordinary people who, under the extreme pressures of this complex and challenging birth defect, lead inspiring lives. In this book we are privileged to peek through a window opened by Cody's mother, Marly Cornell, who tells the story of one such young person who lived with joy, laughter, and dignity. Cody had a zest for life and a tenacity that demonstrates all that can be achieved when one just keeps moving forward. Her encouragement of others to look beyond their preconceptions about her abilities is an inspiration to each of us.

Spina bifida can affect any family, and its complications can influence any number of systems of the body. Children born with spina bifida may face multiple surgeries before they even reach the age of eighteen, and must navigate an array of social and physical barriers in their pursuit of mobility and inclusion. Adults with spina bifida deal with a range of obstacles to a fully independent life. Obtaining adequate and accessible medical care, living accommodations, transportation, education, job training, and employment are all hard-won achievements, particularly in light of the subtle and overt forms of discrimination that are part of the life experience for anyone with a disability.

Those who continue to embrace the joy and fun in life, while struggling for those things that so many others take for granted, are passionate people whose determination and drive is humbling. Cody Jane is a

shining representative of that spirit. Her amazing heart, and her resolve that she could—and would—accomplish anything she set her mind to, poignantly demonstrates the strength that lives within so many of our families. *The Able Life of Cody Jane* compels us all to live with greater courage, to embrace a life rich with humor, happiness, and love. Cody's life was truly an “able” one.

Cindy Brownstein, President and CEO
Spina Bifida Association
Washington, DC
www.spinabifidaassociation.org

Introduction

MY DAUGHTER CODY was always looking for books that told her story—books that said something useful about how others aspiring for independence dealt with real-life challenges that were sometimes difficult, and oftentimes funny. We once talked about writing a book about her life. Cody wasn't convinced anyone would be interested in “some woman who's been through a lot of surgeries and junk.” She did not appreciate the suggestion that she was in any way special.

Cody had no tolerance for anyone's feeling sorry for her. She wanted others to understand “how interesting living a life having to use a wheelchair can be—how the struggles of life may look horrible to the ‘normal’ person, but to us, we are just living—like them.” Disability did not define Cody or stop her from doing what she wanted to do. She focused on love, laughter, family, fun, and helping others.

Three days before her birthday in 2003, Cody sent me this email:

Thanks for giving birth to me, and keeping me, even though I cost so much over the last almost 32 years. A lot of parents give up on their handicapped kids. The ones that don't give up should get praised. Thank you for keeping me. Love you, too. Cody

Her thanks for “keeping” her reminded me of my mother's suggestion right after Cody was born. I recoiled at Mom's idea to place my baby in a “home.” That same day, Tad's mother told him about her prayer that our child be mentally retarded rather than be aware of her birth defect and physical disability. At the time, I was horrified by these reactions. Many years passed before I realized that Cody's grandmothers both responded to her birth with protective intentions. My mother hoped to shield me

The Able Life of Cody Jane

from the difficulties and hardships she imagined we'd face. Tad's mother sought to protect Cody from the suffering she might endure knowing she was "defective." Thirty-two years later I still felt so much gratitude for the life of my daughter. Of course she and I were each wounded by her fear and suffering, and so was anyone else who loved her. But *far* greater than any associated pain was the absolute joy that was Cody.

I answered her email:

You are worth every penny and every ounce of energy I have. You are the most important thing to ever happen to me, and I am the luckiest parent in the entire world. I love your guts, and I am happy that you were born almost 32 years ago. You are a gift to me that God must have loved me very much to let me have.

Chapter 1

The Importance of Dogs and Neurosurgeons

MY MOTHER SUSPECTED correctly that my main reason for marrying in the middle of my freshman year of college in 1968 was to attend the Miami Pop Festival. I wasn't allowed to take a long-distance trip with a boy. Tad suggested marriage, and I agreed. At eighteen, I was completely in love with Tad. Firmly entrenched in the sixties' counterculture, we shared ideals and considered ourselves seekers of spiritual truth and social justice. As the war in Vietnam divided the country, we embraced the peace movement and supported civil rights.

Three days after Christmas, we exchanged wedding vows in my parents' living room. Tad looked handsome in his yellow-tinted wire-rimmed glasses and "good" jacket and tie. His hair hung to his shoulders. I wore a purple minidress. Friends played guitars and a dulcimer. Our wedding gifts ranged from a toaster and a blender to homemade bread and a half-ounce bag of marijuana.

Neither of us questioned that we'd start having kids soon after college. I wanted to be a young mother. My mother was in her forties when I was born. She endured menopause and my tumultuous teen years at the same time.

Sedation during childbirth was customary in standard hospitals in Philadelphia in 1972, so Tad and I chose a maternity center where "natural" childbirth was allowed. When Cody was a small child, she never tired of hearing the story of her first few moments and the way we met. My first look at her was in an envelope of "uh oh."

Cody emerged quietly on a Sunday morning in late August after six hours of labor. The doctor cautioned not to touch the baby's lower back as the midwife carefully placed the five-pound, eight-and-one-half-ounce newborn on my stomach. The physician told me at once that my baby had a congenital birth defect called spina bifida. I asked what that meant. He said he'd get more information right away, but for now he knew she might be paralyzed or brain damaged. He paused before adding, "She might not live." He again instructed me not to touch a dime-sized pink membrane visible on the middle of her lower back.

I looked at the pale-skinned baby lying on my stomach. She was wide awake and calm. Her dark-blue eyes peered up toward my face. I reached for her hand and she grabbed my thumb. I was startled by the strength of her grip. Despite what the doctor had just said, I could see my kid was okay. From that moment Tad and I knew that whatever physical problems she might have, she was fine. She was alert. She was okay. I smiled at Cody Jane.

After a nurse took Cody away to have a protective covering placed over the small exposed area on her back, I was moved to a patient room. Tad and I waited there for a pediatrician to come and tell us more about Cody's situation. Tad called his parents and wept when his mother cried on the phone.

When the pediatrician arrived, his face was so sad I almost cried. He said Cody's legs were paralyzed. She'd been such a feisty kicker throughout my pregnancy—her arms alone must have caused all the movement I'd felt. The doctor said in a sympathetic voice, "We don't know what all might be wrong with your daughter; she might not live." He said Cody needed surgery to close the spot at the base of her spine to prevent infection, meningitis, and further nerve damage. Tad could ride the short distance downtown with her in an ambulance within the hour. Specialists at a university hospital would perform the operation that afternoon.

Cody was brought to me for a moment before they left. I held my hand next to her arm to measure it against part of me. I wanted to remember how tiny she was the day she was born. Her eyes were bright and attentive, her skin soft. I stroked her wispy golden hair and perfect ears.

After Cody and Tad left, a nurse explained that I was put in a room away from other mothers and infants “for my own good” since I was without *my* baby. That nurse was dead wrong; I felt left out.

I couldn't make a long-distance call to my parents from my room. My father had changed jobs and moved the family from the Philadelphia suburbs to Pittsburgh two years earlier. My older brother, Billy, was the only immediate family member still in the area. I called him and left a message.

My father-in-law came to see me and brought a red rose in a small crystal vase. He cried as he hugged me, saying, “I'm so sorry.” I was touched by his visit and gift, but I was also beginning to feel angry. I knew we had serious problems to deal with, but nobody seemed to notice the good part—*I just had a baby!*

I did an ink sketch of the rose in the vase and fell asleep. Tad came back in the afternoon. Cody's back operation was successful; she was sleeping when he left. We would not be allowed to touch her, but we could see her through the glass in the morning.

Early the next day, Tad and I drove downtown to Thomas Jefferson University Hospital to see our daughter. Entering the neonatal intensive care unit nursery, I saw dozens of at-risk babies on the other side of a glass wall, each in a clear plastic drawer-like bed. This was a world I did not know existed. Some of the bandaged infants had undergone surgeries. Some were about to have surgery, like the baby born that morning with his heart on the outside of his chest. I watched the small heart, a living organ, beating in front of my eyes. *How was this possible?* A baby girl was born with her esophagus not connected to her stomach. Another infant with spina bifida had been abandoned in the unit right after his birth. His parents refused to take him home. I learned later that one of the nurses adopted him.

The suffering represented in this place astounded me. After twenty-two years without having anything close to a tragic experience, I now glimpsed a profound and sober reality. I imagined hospitals all across the country and throughout the world with intensive care nurseries full of babies like these. I was amazed I'd not known about them before. Now

knowing, I was overcome with an emotion I could not describe—a feeling like gratitude. I felt honored to be a witness and share the ache and hope for these vulnerable infants.

I walked faster past each baby, looking for Cody. I'd seen her only for a few moments before she was taken away the day before. I hoped I'd recognize her. At the far end of the front row of plastic beds, I saw "Cody Jane" handwritten on tape on a plastic bed where she lay sleeping. A tiny diaper partially covered a bandage on her lower back. I wanted to touch her and feel her soft blonde hair again, but I could only watch her through the glass.

A neurosurgeon explained that Cody was born with the most severe type of spina bifida, called myelomeningocele. There was no indication of feeling or movement from her waist down; she might never have bowel or bladder control. No one could say if she would live, and no one knew what caused this birth defect or whether her brain was damaged.

He explained another, more serious, complication now that the exposed area at the lower end of Cody's spinal cord was surgically closed. There might be a corresponding open area at the top end of her spinal cord, inside her head. If so, cerebrospinal fluid could build up. Increased fluid pressure against her brain might cause permanent damage, seizures, and/or blindness. Cody's head would be measured each day for any sign of faster-than-normal growth.

Tad had graduated from Temple University the previous year and worked as a dishwasher while searching for a teaching job. Since my graduation from Moore College of Art three months earlier, we lived in Bucks County, assisting in a home renovation for my sculpture professor, Robert. We were thrilled when he invited us to move, with our two beagles and two cats, to the country for the few months before the birth of our baby. But now, staying in contact with Cody's doctors was our highest priority.

Tad and I drove the hour from Bucks Country to Philadelphia every other day. I spoke with specialists daily to track her progress and monitor her care. The glass wall continued to separate us from our newborn.

During a phone call with the pediatric resident, I was told Cody had “deformed” arms. Her arms had looked perfect to me. Alarmed, I drove into town to speak with the orthopedic surgeon, who assured me that Cody’s arms were “entirely normal.”

I asked, “Why did the pediatrician tell me that?”

The physician sighed and explained that doctors want to provide information so badly in “these types of cases” that they sometimes “see things that aren’t there, or they make things up.”

Incredulous, I asked, “Make things up?”

The doctor nodded and apologized for her less-experienced colleague.

Within three weeks the neurosurgeon confirmed that Cody’s head was expanding more quickly than normal. He explained our options. He could implant a shunt in Cody’s head. The one-way pump would route spinal fluid through tubing threaded into a vein to her heart. The fluid would absorb naturally into her bloodstream. The doctor said the shunt procedure was relatively new—successful for the first time about fifteen years earlier on a baby boy in Australia. Prior to that, infants like Cody usually died soon after birth.

As the doctor paused to write a note, I remembered singing with my high school choir at a nursing home with the gruesome name, The Inglis Home for Incurables. A man there in a reclining wheelchair had a head the size of a double-long football—too heavy for him to lift. We were told he had “water on the brain,” or hydrocephalus.

Cody’s doctor continued, “The other alternative is not to operate.”

“And do what instead?” I asked, hoping for a less-invasive option.

Without expression, he answered, “Well, you could just wait. She might die.”

Astonished, I asked, “Is that your recommendation?”

“No. But it’s your choice.”

I asked, “You said that without this operation our child will eventually become brain-damaged by fluid buildup, right?”

“Well, of course. If she lives,” he clarified in a flat voice.

Annoyed, I said, “That’s not a choice.”

Cody was taken into surgery for the successful implantation of a shunt in her brain. Another baby born at that hospital around the same time required eleven shunt surgeries in eleven weeks.

For the next three weeks I pressed the doctors to let us take Cody home. We had moved to a small apartment north of downtown in a less-than-prosperous section of Germantown, and Tad had begun a teaching job in a school for “severely and profoundly retarded” adults.

The neurosurgeon agreed that Cody could come home if we could care for the gaping wound on her back. When I saw the incision for the first time, my tiny baby looked like she’d been sawn in half. The surgery to repair the opening on the lower end of her spine left a deep S-shaped open incision that curved from the right side of her waist down and through her left buttock. Dressing changes twice a day required a three-step cleansing and disinfecting process. Healing would take weeks, and the scar would be ugly.

Cody was also sent home with small plaster casts on her feet. She was born with a perfectly formed baby body except for her feet. Both were turned at the ankles as though swept to the left. The casts had to be changed weekly, then biweekly, then monthly for four months. After that, she’d wear a crossbar with shoes to hold her feet straight at night.

The day I held Cody for the first time since the morning of her birth, I touched her soft skin and inhaled her intoxicating baby scent. Watching her through the nursery glass for her first six weeks had been soundless. Tad and I laughed to hear her soft squeaks and coos. Her lips smacked as she sucked on her bottle. She made an audible sigh with each breath as she slept on the ride home.

I carried Cody in a bassinette from the car. Tad walked ahead to open the front door to our apartment. Cody was asleep on her tummy with her head turned to the left, her arms folded up on each side of her head, and her fingers closed in loose little fists. Her pale skin was almost transparent.

As I reached the steps to our door, I looked down at Cody. Her face was blue! She looked dead! I said an urgent prayer, “Please, God! Help!”

Cody's skin immediately returned to its pale color and, in the same second, she smiled in her sleep, a full cheek-dimpling smile. Instantly relieved, I thanked God. This was at once my first truly panicked moment of fear for Cody and immediate answer-to-prayer miracle.

I held Cody in my arms much of each day while Tad was at work. We kept busy with wound care, feedings, diaper changes, physical therapy exercises, kisses, and general entertainment. I tried to paint while Cody napped, but I had to stop before I could squeeze colors on the palette. Her naps were rare and short. I usually collapsed in exhaustion on the bed with her and the dogs.

Cody's first laugh erupted when our beagle, Mort, jumped onto the bed where Cody leaned on a pillow. He sat in front of her, tilted his head, and licked her cheek. Her cascade of deep chortles and squeaks repeated like a machine gun. I entertained her any way I could to see her eyes sparkle and hear that sound. Our dogs were guaranteed triggers for her amusement. Cody watched everything they did with rapt attention. She sometimes fell over laughing at them. Both beagles allowed her to pull their legs, tails, or ears as she reached for them. They licked her face, nuzzled her, and sometimes fell asleep in a pile together. With the dogs' help, Cody learned how to hold her head up without wobbling, roll over and, finally, sit up.

For the most part, I thought Cody wasn't so different from other babies. Other infants couldn't walk or control their bladders, either. An undeniable difference was that she saw lots of doctors: neurosurgeons, neurologists, urologists, orthopedic surgeons, pediatricians, wound care specialists, and a variety of physical therapists and adaptive equipment designers. She saw specialists at Jefferson Hospital and a highly recommended pediatrician for regular baby care.

The neurosurgeon was the most critical member of Cody's medical team. Shunt problems sounded the most life threatening. Tad and I were cautioned to watch for symptoms of a shunt malfunction. Possibilities included nausea, fatigue, headache, and the inability of her eyes to look

up past the midpoint or horizon—a symptom called “sunsetting.” The other symptoms could happen to anyone, so sunsetting eyes became the sign I watched for when Cody was ill.

Tad and I learned everything we could about each assault on Cody’s health. Every new problem brought new treatment techniques. The medicines, procedures, and paraphernalia used to repair my child were both ghoulish and miraculous.

We studied alternative healing approaches to find anything else that might help Cody. Of special interest was information about how children with disabilities learn, and the types of experiences they often miss due to physical limitations—such as outdoor play. In the early spring, we took walks in an arboretum a few miles away. On the ground Cody wiggled forward on her elbows, played in the grass or leaned back on a resting beagle. Cody was nine months old when she spoke her first word: “dog.”

When Cody awoke from a longer-than-usual nap one day in June, her eyes looked funny. I called Tad, and he came home early from work. He agreed that her eyes might be sunsetting. The pediatrician sent us to Children’s Hospital of Pennsylvania (CHOP) in West Philadelphia.

Tad and I followed Cody’s gurney from test to test. A CAT scan showed enlarged brain ventricles due to intracranial fluid buildup. Brain surgery to revise Cody’s shunt was scheduled for the next morning. Tad left for the night and I stayed with Cody. I said silent prayers as she slept in a raised hospital crib in a large room with other cribs. The lights were low. Glass-enclosed rooms on one side were brightly lit where nurses worked on charts or spoke on the phone. I looked around at sleeping babies and was reminded of my first visit to an intensive care nursery. I was back in the company of others living through hard times.

A baby girl not much older than Cody sat in a crib nearby with her eyes open. She had a pretty face and dark hair, but the shape of her head was wrong. Her head hadn’t developed above her eyebrows; she had no forehead. The next time a nurse walked by, I asked her to tell me about the little girl. The nurse said the child had been living at the hospital since birth and wasn’t expected to survive this long. She’d been born with

no actual brain, only a brainstem. She could open her eyes, sleep and breathe, but nothing beyond involuntary brain functions. That a child could look around, but have no thoughts, sounded like science fiction.

I sat in a chair next to Cody's crib and watched her sleep. In the early morning light, she opened her eyes, looked up at me and smiled. Her eyes were back to normal. I quickly called a nurse. I thanked God when the doctor examined Cody and cancelled surgery.

Before we left, a social worker told us about a new CHOP outpatient clinic for kids like Cody who needed care from multiple clinicians. The intent was to coordinate treatment by combined visits with several specialists in one monthly appointment—a sensible idea that could significantly reduce the frequency of doctor visits.

The following week, at the first appointment, the unsmiling pediatrician in charge of the clinic prescribed antibiotics for a urinary tract infection and directed that Cody take them on a permanent basis. When Tad and I questioned that, the doctor firmly stated that kidney infections were the most serious threat to Cody's health. Driving home her point, she added, "That's what *kills* these kids!"

Tad and I were instructed in the "Crede" technique. We were shown how to press on Cody's lower abdomen above the pubic bone to empty her bladder completely with each diaper change. The technique was intended to prevent buildup of bacteria in her urine that wouldn't fully flush out otherwise. The doctor said the harmless method wasn't uncomfortable. The first time I pressed down, I was afraid I might hurt Cody. But she didn't seem to mind.

Cody was eleven months old in mid-July when Tad's college roommate, Barry, invited us to his parents' home in New Hampshire for the weekend. He suggested a hike in the nearby White Mountains. A nature hike was the type of experience I'd read that kids with disabilities rarely have. As we drove north into New England, Cody laughed watching the dogs' ears flutter in the wind as they leaned out the car window.

When we arrived, Barry's father, a chiropractor, offered to examine Cody and x-ray her spine. He saw a twist in her pelvis and made an adjustment that successfully aligned her hips. As he lifted Cody from the padded table,

her legs extended straighter. Her feet appeared to hang evenly together for the first time! Barry's father explained that with proper alignment of her spine, Cody might show improvement in other areas as well. He offered to identify a colleague in our area so Cody could continue the good progress when we returned to Philadelphia. This new development was exciting.

Barry had chosen Mount Jefferson for our hike the next morning. He and his fiancée Judy were experienced outdoor folks. They had canteens, cooking gear, rope, a large plastic tarp and tent, and maps of the trails. Barry assured us that the well-worn path up the mountain was easy going for novice hikers. We'd pitch the tent and sleep overnight on the summit of the second largest mountain in the Presidential Mountain Range.

As Barry described the distance we'd walk, I realized it wasn't a good idea to take both dogs with us after all. Sadie was a healthy two-year-old. But Morty, at age eleven, had arthritis in his hind leg. I didn't want to exacerbate his discomfort or risk injury. Barry's parents offered to keep Morty while we spent the night on the mountaintop.

Tad carried our supplies in a backpack, and Cody perched in a baby carrier on my back. I breathed in fresh mountain air as we started up the trail. The rhythm of my steps on the dirt path lulled Cody to sleep. The sun shone on the glossy black fur on Sadie's back. Her tail wagged in tempo as the six of us made our way up the mountain.

The trail had been on a winding but steady incline for more than an hour when we discovered that none of us had filled our canteens. Barry pulled out the map and suggested an alternative trail that wound sideways to the closest water source. We agreed we'd gone too far to go back down the mountain, so we set out for the stream. Cody slept during the long detour.

Our path crossed some loose rock on a steep slant. I stepped out onto the scree, lost my footing, and felt sheer panic for the split second it took to grab a tree branch and regain balance. In that brief instant, I pictured Cody tumbling out of the back carrier and down the mountain. I cringed to realize I'd put her at such risk. *What was I thinking to bring her up here?*

Too late to turn back, our only option was to keep moving toward drinking water. Tad and I switched packs. I carried the heavier supply pack; he carried our precious cargo. I walked close behind and kept my

eye on Cody as the adrenalin coursing through my body slowly dissipated. Sadie never lost her footing and trotted on without hesitation.

The sun was directly overhead when we reached the stream. Sadie put her paws in the sparkling cold water and took a long drink. I filled a bottle for Cody, gulped water by the handful, and filled canteens. We sat down and pulled out snacks. Barry unfolded the trail map to plot our next move. Reaching the summit before evening wasn't a realistic expectation in light of our detour. He recommended heading for the emergency shelter for the night.

After another hour on the trail, we came to a wooden sign with a warning: *Set up camp before dark or turn back! People have been known to die of exposure on this mountain even in the summertime.* That sounded ominous, but the afternoon sun felt warm. We decided to step up our pace. The steepness of the less-traveled path looked like more than Sadie could maneuver at points, but she plodded onward and upward.

Our progress was a little slower when the sun moved past the top of the mountain, leaving us in shadow and imminent darkness. None of us expected such an abrupt change. We continued on until, without warning, it began to rain. Looking up, it was clear that going forward required using rope to pull us over the next ledge. Our hiking party was stuck on a slanted area about six-by-six-feet square. Fat raindrops splashed us, and thunder began. There was no time to set up camp. Barry pulled out the plastic tarp and we scurried to stretch out underneath before the ground was drenched. Our only choice was to stay put, do without dinner, and try to sleep until daybreak.

The four of us lay side by side. Cody lay quietly on my stomach. Sadie cuddled between Tad and me. Barry was closest to the outside ledge. He suggested we tuck our hiking boots under our right sides to prevent rolling over the edge in our sleep.

Cold rain battered the plastic tarp. Lightning flashed to our side and down the mountain. I hoped the thunder and drumming rain muffled my voice when I whispered to Tad that I was scared. He turned and put his arm over Cody and me. Tears slid down the sides of my face. I was truly terrified. I couldn't tell if Barry or Judy slept, but they were silent through the night.

The storm carried on for several hours. Cody's diaper was saturated; my denim shirt was soaked with warm pee. But I could not move to change her. Safety lay in holding still and trying to sleep. I saw an occasional flash of lightning reflected in my daughter's trusting eyes as she looked up toward my face. I prayed for God to rescue us, to bring us safely off this mountain. I wanted to be way below in any of the tiny houses I knew were down there from the twinkling lights I'd seen in the distance before the downpour. I was glad Morty was spared this experience. I imagined him safe, dry, and curled up asleep.

The rain stopped sometime in the night. The moment it was light, we climbed out from under the tarp and folded it into a pack. The sky was blue and cloudless—the start of a gorgeous sunny day. Barry used the rope to climb up over the ledge, where he discovered that we were above the tree line. He came back down for Sadie, tucked her under his left arm and pulled them both to higher ground with his right arm.

Tad secured Cody in the backpack and he, Judy, and I climbed up over the ledge. Once on open tundra, Barry used twigs to coax a campfire. Within minutes, a park ranger appeared wearing shorts, hiking boots and a wide-brimmed hat. He said fires weren't allowed in the protected tundra. He kicked dirt onto the still-tiny flames, explaining that flora on the tundra was so fragile that a campfire could destroy what took thousands of years to grow. As the ranger pointed to miniature plants, moss, and flowers growing between the rocks, I coveted his clean khaki shirt. While he wrote a ticket and attached a hefty fine, I thought, *Where was this guy last night when I thought we might die on the mountain?* Out loud I said, "We were stuck on a ledge all night during the thunderstorm."

"You were lucky, ma'am." He folded the citation and handed it to Barry. "Three people fell down the ravine in the past week; they all died." *Yikes.*

The ranger left as quickly as he had appeared and we repacked our supplies. Since Cody's food was in small jars and Sadie's dry food was in a plastic bag, they were the only ones who ate that morning. As I spooned applesauce into Cody's mouth, her lips smacked, and I pondered the danger we'd survived. *That could have easily been us tumbling down a ravine.*

Once packed up, we looked around at the field of boulders between

our current location on the craggy tundra and trail markings that resumed in the distance. Between the large rocks were wide gaps and deep fissures. With no indication which direction led to the trail, we each attempted different routes and repeatedly met with crevasses too wide to cross. The giant rocky maze stopped us at every turn. Dear little Sadie solved our dilemma and earned respect from our seasoned hiking friends. She wound methodically across the broad expanse, leading us back onto the trail. We never did see the emergency shelter.

When our hiking party arrived at the mountain's summit, at an elevation of more than 5,700 feet, we marveled at a view that went for miles into the distance. I lifted Cody out of the back carrier and pointed to the far-off horizon in several directions. She looked with interest everywhere I pointed and seemed to agree it was special.

After our night on the ledge, we chose not to linger any longer than it took to eat a quick meal and pack up. The five-mile direct descent went fast. Once at the bottom, I looked back up at magnificent Mount Jefferson. I cringed again to think I'd taken a baby and a dog up there and clung to a ledge for hours amid booming thunder and lightning. But we'd escaped unharmed and the sun had shone brightly in the morning. Our small dog had turned out to be an essential member of our hiking team. Perhaps without the detour to find drinking water, our trek would not have been so precarious; but I'd never forget how vulnerable I felt and how frightened I was for my precious family that night on the ledge.

Chapter 16

Blue, Sex, and Action

IN MID-OCTOBER I was working on a series of paintings when Cody called from school. “Mom, you have to come here now. You won’t believe the dog that’s here. I’m waiting for the bus to go play hockey. Please come, Mom. He doesn’t have a collar, he’s thin, and he’s the smartest dog I ever saw.”

“Cody, I’m so busy right now. He probably lives in that neighborhood.”

“Please, Mom, this dog is special. I don’t think he has a family. Please? The bus will be here any second. I’ll have to go.”

“Okay, babe.” I dropped my brushes in a pot of water and put the fresh-squeezed globs of acrylic paint in the freezer. South High was only five minutes away.

The schoolyard was empty when I arrived—except for the adaptive hockey team. Nine players stood in a line, waiting for the bus. I noticed some new kids this year. Cody was the only one in a wheelchair.

“Mom, watch this.” A medium-sized black dog ran from the field and dropped a stick in front of a boy wearing an ankle brace. The dog stepped back, crouched in play position, and waited. The boy tossed the stick. The dog brought it back and put it at the feet of a boy in a helmet. He threw the stick, and the dog brought it to the feet of the next kid. This continued until the dog came to Cody. He put a paw on her footrest and gently dropped the stick on her lap.

“See, Mom? See how smart he is? He’s so sweet!”

The bus arrived just as Cody threw the stick. She rolled onto the wheelchair lift and into the bus. The attentive black dog dropped his

stick at my feet and waited. I tossed it as I scanned the area for anyone who might recognize him. I walked one way, then the other. The dog stayed close, coaxing me to throw his stick again.

I decided to ignore him and walk to my car. As I opened the car door, he raced past me, jumped in, and sat in the passenger seat, facing forward, ready to go.

At home, after friendly sniffing with Milka and Dan, he wandered through the house. When he perched on his hind legs to look at individual paintings on the walls, I was dumbfounded.

When Cody came home from school, the dog raced to greet her and put his front paws in her lap. She hugged him and said, "He looks like a big Milka or a giant Dan." He looked so similar to our dogs; we assumed he was a cockapoo. That's how I listed him on the "found dog" notices. Cody said, "I wish we could keep him, Mom. He's so smart!"

"A dog this terrific is probably somebody's best friend."

She begged, "If nobody claims him, can we please keep him?"

I said, "We'll see. Three dogs . . . is a lot of dogs."

I called the pound weekly and scanned the newspaper for lost-dog notices. Two weeks later, I read: LOST: BLACK COCKAPOO, female, etc. I was so relieved to see "female," I realized I wanted to keep the dog, too. Dennis named him Blue.

Dennis, Cody, and I flew to Pittsburgh at Thanksgiving to see my father after his heart surgery. Cody sat with Dad and we all tried to keep him comfortable.

We rented a car for a quick trip to Philadelphia. Cody saw her former teacher, Mrs. R, and contacted her old boyfriend, Ryan. We spent an evening with my friend Jackie and her teenage son, Lee. On the plane home Cody said, "Let's move back to Philly. There's good music on the radio, good friends, and cute boys."

Days later, Cody had a bad headache. We figured it was from uncomfortable beds on our trip, but when the pain worsened we were directed to the emergency room. We stopped on the way to the hospital for a chiropractic adjustment to Cody's neck, just in case.

In the ER, tears streamed down her cheeks as surgery was arranged.

Cody said, "I'm only afraid of three things: looking stupid in hats to cover my shaved head, death, and apnea."

Her use of the word "only" and her grouping together of hair loss, death, and apnea made me laugh. She laughed, too.

Dennis, Cody, and I said a prayer together for complete healing and, within an hour, all shunt problem symptoms disappeared. The neurosurgeon sent Cody home. Despite such a marvelous miracle, the initial panic Cody experienced during this emergency stuck with her for several days. She suggested, "Maybe I should go see Dick."

Dick was a marriage counselor Dennis and I had seen a few years before. I'd recently begun seeing him again. He arranged for a female colleague to help Cody deal with the realistic fears in her life and for her life. Cody said she liked having her own therapist.

After Dennis spent most of January in Australia he initiated talk about our moving to Oz after Cody finished high school. She didn't like that idea. He discussed it further with her while I visited friends one weekend in March. Cody's voice quivered the night I returned home. "I told Dad I don't want to move to Australia. I don't want to be so far from my friends. But he kept trying to convince me. I don't know if I'm even safe there. I have to know there are good enough doctors and hospitals in case I need surgery."

I assured her, "No one will force you to move to Australia. And we won't move anywhere that doesn't have excellent medical care for you."

Dennis was reading in bed when I brought up Cody's concerns. He lowered his book and said, "By the time we move to Oz, Cody will be eighteen. She'll be able to live on her own; she doesn't have to come. The long flight and quarantine regulations are too much for the dogs anyway. They can stay here with her." My heart began to beat a little faster.

I told Dennis, "I don't want to live that far from Cody or the dogs. If she had a medical emergency, it would take too long to get to her. She always needs an advocate. You know bad things happen in hospitals."

"She's only in tenth grade. There's time to think about it." He went back to his book.

The idea of living in Australia without Cody or the dogs horrified me.

I hoped my husband would change his mind by the time Cody finished high school. I wasn't sure what I'd do if he didn't. I couldn't imagine living so far from Cody. I looked over at Milka curled in her pink dog bed. Dan lay next to me, licking his paw. Blue was asleep beside him. Each dog was a treasure—for me and for Cody. I put thoughts about a move to Australia out of my mind.

A few days later Dennis was in Baltimore. I was reading in bed when Cody came into the room and said, "I think I do have an ulcer. I feel better with those pills."

She'd started a prescribed antacid medication for frequent stomach-aches. I asked her to tell me more about what things made her nervous.

"I get too shy around boys I like. I don't know what to say."

"You can talk to boys who are friends, right?"

"That's different."

"The best way to get to know a boy you like is to be friends. Even if it doesn't become romantic, you still have a friend, right?"

"I'm friends with Lewis and I like him as a boyfriend, too. But he has another girlfriend. He makes me so mad. He treats me weird at school sometimes. I'm afraid I'll never have another *real* boyfriend again, like Ryan."

"You were *seven* when Ryan was your boyfriend. Being a teenager is more complicated."

"Tell me about it!" Cody rolled her eyes and smiled. She asked, "Is there any reason I can't have babies?"

"You can get pregnant the same way anyone does. Some things might be harder to do while you're pregnant since you can't walk. I don't know what it'd be like for you to give birth. It might be hard to push a baby out. But you could have a cesarean where the doctor makes an incision in your tummy to get to the baby."

"No surgery," Cody said. "I've had enough surgeries."

"I really don't know enough about it, honey. But we can find out more. We'll ask a doctor. We need to find some older women in wheelchairs, so you can ask them how they handle boyfriends and sex. Maybe you could get some tips."

“Mom! You can’t just ask people how they have sex!” We both laughed.

“Okay, we’ll find some books or videos about relationships and sex for people with disabilities.” Cody liked that idea.

The next day I began calling libraries, advocacy organizations, and the human sexuality program at the University. I made calls all over the country, following a trail of referrals, and found little to help Cody. I ordered books on sexuality for people with disabilities. Cody and I were disappointed to find that each book focused primarily on paralyzed men, penile implants and pumps. There was scarcely anything about sex for women with disabilities. A few books mentioned that a sense of humor was helpful during sex when one or both partners have disabilities, especially if incontinence was a factor. There was no guarantee that a person wouldn’t pee at the wrong time. Being squeamish about bodily functions could hamper the experience.

Two of my girlfriends had physical disabilities, but neither was in a wheelchair. Neither knew of any helpful materials or books on sex. One friend told me, “The first guy I had sex with wanted me on top. I couldn’t hold myself up in that position; I was horribly embarrassed. I could’ve used a book like the one you’re looking for.”

I called a local nonprofit support organization for parents of children with disabilities. The woman I spoke with apologized. She said that members of their group preferred to think of their children as “asexual.” “Many of our parents are afraid that sex is not in the cards for their handicapped child anyway. It’s a messy topic.”

Cody and I kept talking and reading, and studying materials we found. We both grew increasingly frustrated and angry that resources focused only on men. Cody’s sensitivity to discrimination against women intensified as she noticed sexist language in magazines and TV ads. She pointed out to me when she heard someone make a sexist comment. She asked me to buy her a *Playgirl* magazine.

As Cody became more attuned to issues of fairness, she spoke up when confronted with barriers. If a store was not accessible for a person in a wheelchair, Cody asked to talk to someone in charge to voice a complaint. When she ordered tickets by phone for a concert, a ticket agent repeated back, “So you need tickets for two people and a wheelchair?”

Tired of being referred to as “a chair,” Cody firmly repeated, “No, I need three tickets, and one will be used by a *person* in a wheelchair.”

The ticket agent repeated, “Right, two regular tickets and one chair. The wheelchair will be in the handicapped section, and the two people will sit in the row behind the chair.”

Cody argued in frustration, “I want to sit with my parents, not in front of them.”

I took the phone. “Look, my husband and I want to take our daughter to this concert as a special occasion. We want to sit together, enjoy the concert *together*. Can that happen?”

The best we accomplished was one folding chair next to Cody in the handicapped section. Due to the inflexibility she encountered buying tickets, Cody often attended concerts with friends with disabilities rather than with those who couldn't sit with her.

Cody's interest in and concerns about sex prompted me to visit the adult section of a video store. I hoped to find something educational that addressed sexuality for people with disabilities, something that provided sex information without being pornographic. Dennis came with me. We scanned shelves, looking for films made by academic institutions. Video jackets showed photos of balloon-sized breasts and couples in erotic poses. I was ready to give up when I found a video narrated by a family therapist claiming to demonstrate sexuality for “normal” married couples. I told Cody, “We couldn't find anything about sex and disability, but we rented a video that shows a couple having sex. Do you want to watch it?” She said okay.

Dennis turned on the VCR. The film began with a discussion of “normal and natural, healthy sexuality between a loving husband and wife.” The narrator said, “It is perfectly fine to try different positions while having sexual relations.” She stressed that anything a couple finds comfortable, and does not cause harm, is appropriate during sex. The “husband and wife” appeared to be having intercourse, demonstrating a variety of positions. Oral sex was described as a “nice” alternative that did not risk pregnancy. Nothing the couple did conveyed even the slightest hint of passion. Far from pornographic, the portrayal was so antiseptic

that sex came across as unnatural and robotic. After ten minutes, Cody turned around and said, “Do you mind if I stop watching this? I think I might throw up.”

“Thank you!” Dennis responded and turned off the VCR.

I burst out laughing, “I’m sorry, honey. That was pretty terrible.”

When school was finished in June, I joined Dennis on a business trip to Vancouver. Amy and Kari stayed with Cody. The girls promised to be responsible, share meal preparation, and care for the dogs. Robbie offered to be available in case of emergency. I called home the first night and Cody cheerfully told me how the dogs were. I asked about her first day of work.

She said, “I don’t know if I want this summer job.” She described each thing she did at work, and how some of it was hard. Sighing, she said, “I don’t think I can do it.”

“It’s just the first day, babe. Take your time. You’ll get the hang of it.”

Cody interrupted, “We might go to Norma Jean’s on Tuesday night. We want to go to a real night club and listen to music.”

I cautioned, “Teenagers might not be allowed without an adult, honey. It’s a bar.”

She said, “We’ll call and find out. I hope we can go.”

I was relieved that Cody was fine. I’d found it hard not to worry about her over the past year. Not knowing when another medical emergency might occur was sometimes a strangulating threat. After I hung up, I told Dennis, “I need to shed this worried feeling, but I forget how.”

Dennis said, “She’s fine. She’ll be fine.”

“I know. *She’s* not the burden. These *feelings* are the burden.”

A few weeks after we came home, Cody decided to take Dennis’s last name. When he adopted Cody, Dennis didn’t think it necessary to change her name from Cornell to Ahlburg. She had toyed with the idea before, but now she was sure. “Dad saved my life, Mom.”

A lawyer friend started the process. Cody wrote a letter explaining her decision to Tad. She revised it several times before sending it. When she went to camp in July she registered as Cody Ahlburg. When she called home she said, “Camp is boring; I don’t want to come back next year. I

learned how to transfer from the floor to the camp bed—and it's higher than my bed at home!" Almost an afterthought, she added, "I like it that everyone here calls me Cody Ahlburg."

In a letter from camp she wrote, "I don't miss you, but I love you. I thought I had feeling in my foot today, but it went away, rats! I don't mind being away from home, but I wish I was away from home somewhere else, like in the arms of a certain young guy." She was referring to my friend Jackie's son in Philadelphia. A homemade calendar in Cody's room had a picture of Lee on every month.

After turning seventeen, Cody began St. Albert's confirmation classes, which were held in a building that was not wheelchair accessible. The priest in charge of the classes, Father Tom, made sure Cody was safely lifted in and out of the building, but she was more and more uncomfortable with the arrangement. A weekend retreat was scheduled in another inaccessible location. Cody wrote a letter to Father Tom, explaining her decision not to attend.

September 22, 1989

Dear Tom,

I originally planned to write to inform you that I have another commitment the weekend of our retreat. I don't have that commitment anymore. But as I was considering this other weekend school trip, it got me to thinking. I don't really feel my needs to feel safe and to feel independent are being met. I think that the meetings and retreats could be held somewhere other than places I can't get to or around in completely, so that I, or anyone else in a wheelchair, could spend the night and do things like everyone else.

Maybe I do have a father and mother who can get me up a few stairs, and do other extra things, but not everybody in a wheelchair has someone to do that for them. I don't feel safe in situations where I can't take care of myself completely. So this is why I've decided not to go on any retreats unless it is to a place where I can stay the whole time like everyone else. I know that you have been trying to make exceptions for me, and trying to fit me in. I appreciate what you have done. It's just

that all my life, I've had exceptions made for me. I want to be treated like everyone else, and do everything like them too. So that's the reason I won't be going on the retreat after all. My mom says to keep the money even if someone else goes in my place.

I would like you to accept this letter as my October 1st report about a social justice issue. The problem I see is that people with disabilities are being excluded from St. Albert's Confirmation Program.

The solutions I propose are: Hold the meetings in places that are fully accessible to everyone. Do not plan an important activity that excludes a disabled person from full participation. Do whatever is possible to make a disabled person feel as important as anyone else.

What I learned is that even people with very good intentions who try to include a disabled person can make the person feel left out without realizing it. I also learned that disabled people have to stick up for their rights every day.

Sincerely,

Cody Ahlburg

The church service that Sunday was held outdoors in nearby Brackett Field. After the service Father Tom came straight over to Cody and thanked her for her letter. He told her she was right; the confirmation program was being moved to an accessible location. Cody gave Tom a shy smile and said, "Cool. Thanks."

At home later, Cody said, "Mom, I want to buy you a suit."

"Sweetie, suits are expensive; save your money." I was starting a half-time job working with psychiatrists in a hospital, and my new position required business attire.

"Mom, I've noticed over the years that you spoil me; you give me a lot. I seriously want to buy some clothes for your new job. I have lots of savings from my birthday and Christmas money, and my summer jobs."

"Okay, then, thank you." I kissed her and said, "Let's go shopping!"

Cody sang in a choir concert the evening of my first day in the new job. I wore the knit suit she bought for me. Cody was the only singer in a wheelchair. She looked beautiful in the spotlight in her blue choir robe.

After thirty hours of prerequisite classroom instruction at a driving school, Cody was ready for behind-the-wheel lessons. A nearby resource center for people with disabilities provided lessons in cars equipped with hand controls. On the day of Cody's final lesson, the teacher invited me to ride along in the backseat.

Cody followed the rules of the road, but slowed almost to a stop a few hundred yards before any intersection. The teacher prompted her to keep going, but Cody hesitated. When Cody turned her head, she also turned the wheel. My heart jumped to my throat a few times on that short trip.

When Cody was little, she sat on my lap and pretended to drive the car. I controlled the gas and brakes as we drove up and down a driveway or in an empty parking lot. If we came close to an obstacle, I'd say, "Whoa! Whoa!" and Cody shrieked with laughter. Now, Cody said she felt nervous driving.

I suggested, "We can't afford a car with hand controls yet anyway. When we can, we'll go to a big parking lot and practice, practice, practice." We were both okay with that idea.

At the Homecoming Pep Fest at Cody's high school, a caged young tiger was paraded through the gym in front of 1,500 cheering students. Cody was appalled to see the frightened animal cower in the small cage. She wrote to the principal. "It is extremely mean to bring an animal locked in a cage so it can't hide or protect itself from a whole bunch of screaming people. Mr. Lewis, we are all animals, and I care deeply for the four-legged ones in this world. I do not like seeing them suffer and put through that fear."

Another version of the same message from Cody was published as a letter to the editor in the student newspaper. She then invited me to her civics class to make a presentation with her on animal exploitation. She had arranged for us to do a similar program the previous spring.

Doing things like that with my daughter caused me to reflect on activities I did as a child with my mother. The only special thing I remembered doing alone with Mom was seeing the movie *Old Yeller* when I was seven. I decided to do more memorable things with Cody. I asked, "Where would you like to go, just us, on a mother-daughter trip?"

Without pausing she said, “Disney World!”

I updated Cody’s health summary and identified a hospital in Orlando with the best pediatric neurosurgeons in case of a shunt emergency during our getaway. Then Cody and I had a nonstop four-day vacation in Disney World.

Our only problem occurred the day we arrived. A wheelchair didn’t fit in the bathroom of the “handicapped accessible” room at our motel two miles from Disney World. And the sidewalk in front of the room entrances had no curb cuts. We were moved to a different room, but the new room’s bathroom didn’t accommodate a wheelchair, either. Cody had to transfer to the floor to scoot-crawl into the bathroom to bathe each morning.

At MGM studios we wore sombreros and sang “Groovy Kind of Love.” We dressed as rock stars for a *Rolling Stone* magazine cover. We watched a TV show taping, a stage show, and saw how special effects were created for movies. All in all, it was a chummy time.

Cody said she noticed how different it would have been had Dennis come along. We would’ve seen different exhibits and not visited as many gift shops or food carts. A big difference for me was doing *all* the lifting of her wheelchair in and out of the rental car and maneuvering in first-aid stations and bathrooms. Though hard on my neck, the fun Cody had was worth it. She said, “Neither of us yelled or got upset about anything.”

Cody wrote a full summary of our trip in her journal and noted, “I think it’s a good idea for mothers and daughters, and fathers and sons, to do things and go places together. I think Mom and I should do this every year. Even though my mom gets crabby sometimes, she is wonderful all the time. I’m noticing as I’m getting older that she’s a great and understanding friend and mom. Well, that concludes my trip with Mom.”

She told Dennis, “Next time, we should all go to Disney World, Dad. You’d like it.”

Chapter 22

Dating

CODY REQUESTED a new computer for her twenty-second birthday. She wanted to surf the Internet and download games. Ernie, now in a computer-related job, found a new PC for her at an auction. She gave her old computer to an attendant. Cody now spent hours surfing the Net, playing games, and honing her typing skills in hopes of finding another office job. Now when we chatted on the phone, I heard her keyboard clicking as she played early generation games like *Ms. Pac-Man*, *Slingo*, or *Where in the World Is Carmen Santiago?*

The Internet made it possible for all kinds of people to meet each other without physical appearance affecting their first impressions—an important issue to those who know how it feels to be judged and misjudged due to physical differences. This served as a great equalizer for people with disabilities. The Internet widened Cody's world, and her circle of friends multiplied. Talking to others with disabilities, she asked and answered questions on topics that might have embarrassed her to discuss in person. Ernie and I first learned about chatrooms from Cody.

At Thanksgiving, Ernie and I took Cody to Pittsburgh to see Mom. In the eleven months Cody had been living in her own place, she'd gained weight. Even with the doors off the hinges, her new wheelchair didn't fit through Mom's doorways. The first morning, Cody scooted from the bedroom toward her wheelchair in the hall. Ernie had often lifted Cody into her chair if needed; but this time, he couldn't. I knelt on one side of Cody and together we struggled to lift her. The three of us barked

instructions to each other as we pulled and floundered in different directions. Cody shouted, “Everybody *stop!*”

While we were frustrated and annoyed with each other, Mom came into the hall and said, “Move over; I’ll pick her up.” Not that Mom was feeble by any means even at age eighty-six, but the idea that she could lift 140 pounds, which we together couldn’t, made us all laugh. Undaunted, Mom reached under Cody’s arms with complete confidence. Despite Cody’s willingness to be lifted, she remained firmly seated on the floor. “Oh my!” Mom frowned.

“It’s okay,” I said, “we’ll go back to basics.” We used the old wheelbarrow technique, lifting Cody’s ankles as she crawled forward on her elbows. She pulled herself onto the living room couch and into her wheelchair. I untangled her legs as she turned around in the seat, and this method worked for the remainder of our stay.

I worried about Cody’s weight increase as it became harder for her to move around and do things for herself. Her breathing was strained more easily when she exerted herself, and some transfers were more difficult. I was careful to broach the subject only in the context of health and mobility, but she responded with annoyance, “Yeah, yeah, yeah. I know.”

Sometime that winter Cody was injured during a transfer from her wheelchair to her bed. The second to smallest toe on her right foot snagged on something and was almost torn off. Cody discovered the injury a day or so later when she saw blood on her sock. Her PCAs bandaged the toe daily for weeks, but by Valentine’s Day her doctor was concerned that the slow healing could be due to diabetes. A test ruled out diabetes, but Cody’s scare lingered.

Cody called later that night. “Hey, Mom, that doctor almost ruined Valentine’s Day . . . but my day *improved.*” A man had asked her out on a date—a “real” date she said, with a forty-year-old who lived in her building. She sounded like an excited teenager. But after her dinner date, Cody decided they’d probably just be friends.

By late April an infection had developed in Cody’s toe. When the doctor said it had to be amputated, Cody sobbed. Her eyes flashed. “I’ll look like a freak without a toe!”

I tried to convince her that losing a toe was not such a big deal, but I truly shared Cody's sadness and anger. Few parts of my daughter's body were untouched by injury or surgery of some kind: her head, neck, back, legs, abdomen, feet, and now her toe. Loss of a toe was not life-threatening, but it was yet another loss. I told Cody how sorry I was and added, "At least you won't need anesthesia since you can't feel your foot."

She brightened a little, then whimpered, "I'll never be able to wear sandals again."

Cody asked Ernie to be with her for the day surgery. He held her hand and distracted her from the procedure. I was grateful. I didn't want to watch or, more to the point, try not to watch.

Cody's favorite PCA resigned that same week and a guy she had a crush on moved out of the building. I felt so sad for her losses and worried that she was depressed. Two days after the toe amputation, I stopped by with a cheer-up gift. Cody was sitting at her kitchen table, her bandaged foot resting on the raised pedal of her wheelchair.

I had again underestimated Cody's resilience. She was in high spirits. Her eyes sparkled as she grinned. "Look at this!"

Cody had sculpted a small toe with flour and water, and painted it to look real. It stuck out of a piece of gauze stained with red food coloring tucked into a clear plastic culture tube. The hospital sticker with Cody's name was taped to the tube. As I looked closely at the fake toe, Cody said, "I'm going to send it to Dad in Hawaii with a note that says: Since you can't be here with me, I'm sending a little part of me to be with you." We both burst out laughing.

Still giggling, she said, "My new attendant thinks it's gross."

"Well, yeah," I agreed, "it's amazing. It looks real."

Cody kept laughing as she told me about her friends' reactions. "Half of them think it's a totally funny thing to send Dennis. The rest think I'm a sick-o."

I offered, "Hey, I have some stuff we could use to make a toenail. I'll bring it tomorrow after work. Then we'll mail it to Dennis."

Cody said, "Cool." We kept laughing and imagining Dennis's reaction.

The following day, the fake toe was missing. We searched every

possible place in Cody's apartment, but the toe was gone. She suspected that her new PCA threw it in the dumpster. Just as we gave up the search, Tad called to confirm his visit in May. Cody told him about her aborted plan to send a fake toe to Dennis on sabbatical in Hawaii.

Tad said, "Cody! That is so gross. Don't you *ever* do anything like that to me! *Ewww!*"

Cody laughed again and said, "You just don't understand my relationship with Dennis. He'd think it was funny."

Tad insisted, "No way, Cody. That is *too* gross!"

After she hung up, Cody giggled and said, "And I thought he was the *fun* father."

Dennis later told Cody that he probably would have been grossed out at first, but then he would have thought it was really funny.

Cody said, "I knew it."

Cody had a bad cold in September. I called at bedtime to see how she was feeling. She said in a stuffy voice, "I don't feel too good."

"Do you have a fever?"

"No. I'm just clogged up. I took some vitamin C and had a cup of tea."

"Okay then, sweet dreams, babe. Say your prayers."

At 2:00 a.m. the phone rang, and I jumped to grab it. Cody said in alarm, "Mom, I can't breathe! Come right away!" and hung up.

I dialed her number quickly and she answered, crying.

"Cody, tell me what's wrong!" I couldn't understand her answer through her sobs and gasps. I spoke strongly, "Cody! Talk to me! If you can't breathe, we need to call 9-1-1."

"No!" Her voice shuddered as she tried to stop crying. "I'm okay. I just need help."

"Are you sure you're okay?"

She cried, "Yeah, I'm okay. I'm just having trouble. I can't find my inhaler, and my bed's wet. I want you to come."

As my panic dissolved, I spoke in anger. "Listen, Cody, I will come. But don't you *ever* call and say something like you can't breathe and hang up! Besides, you don't need to freak out to get me to help you. Just be truthful about what's wrong, okay?"

She whimpered, “You’re coming now?”

“Yes. I’m getting dressed. I’ll be there in fifteen minutes.”

“Thanks, Mom.”

By the time I arrived at Cody’s apartment, she was in her wheelchair. Her eyelashes were still wet with tears, but she felt fine. I found her inhaler in a drawer beside her bed amidst vitamin bottles, snack-food wrappers, makeup, and craft supplies. She took a puff. We had a serious talk while I changed her sheets. I used a stern voice to bring home my point. “Cody. I really mean this. I *never* want you to call at two in the morning, or any time, to tell me you can’t breathe! I mean it, Cody. You need to dial 9-1-1 *immediately* if you can’t breathe. I can’t get here as fast as an ambulance. And *I* can’t help you breathe if you’re really in trouble. I want you to get *real* help when you need it. I need to know that you understand what I’m saying.”

“I do. I will. I’ll call 9-1-1 first, if I really can’t breathe.”

“Promise me.”

Cody looked up at me sincerely and said, “I promise.” She rolled from her wheelchair back into bed and I kissed her.

She said, “I’m sorry you had to come in the middle of the night.”

“That’s okay, sweetie. I’m glad you’re feeling better. Keep taking vitamin C for your cold. And drink lots of water tomorrow.”

“Okay.”

Two weeks later, the phone rang again at 2:00 a.m. and my heart skipped a beat.

Cody spoke fast, “Hi Mom! I’m fine! I just couldn’t wait until morning to tell you. I just made out with a guy! I just had my first truly romantic kissing.”

“That’s great, babe.” I tried to wake up enough to talk more. “Is he still there with you?”

Her enthusiasm barely contained, she said, “No, he just left.”

“Are you okay?”

“Oh, yeah! We made out for a couple of hours! It was great!”

“That’s terrific, sweetie. I’m really glad you had a good time. Is it okay if you tell me the details when I’m more awake?”

“All right!” Cody added a little squeal and said, “I’ll call you in the morning.”

I hung up the phone. Ernie was almost awake, looking at me. “Is she okay?”

“Yeah. She made out with a guy; she’s excited.” Ernie fell back to sleep almost instantly. But I lay awake thinking how happy Cody sounded and how grateful I felt that she still wanted to tell me her good news. I almost called her right back to hear the details.

The instant I arrived at work in the morning, the phone rang. Cody told me more about the guy. He was forty-one; he had cerebral palsy. Most of the kissing took place while both of them sat in their wheelchairs. Cody added, “He’s not really handsome, but he’s really sweet. He’s coming over again tonight. I can’t wait.”

I asked how she met him. Cody gushed on like she had in high school when describing boys she liked. “He was a friend of the guy in the building who I used to have a crush on. I hung out a lot with them. Here I was, gaga over my friend, and all the time this guy was gaga over me! I couldn’t believe it!”

He had come over to watch a movie with Cody and turned off the lights so the atmosphere felt like a movie theater. He moved closer and closer until his arm was around her. Cody said, “When he started to kiss me, I stopped him for a second. I asked if he was going to do the tongue thing. He said ‘No’ and I said ‘That’s good, because I have to warn you, I have a powerful gag reflex.’”

I laughed and teased Cody about gagging not being too sexy.

Her date wanted to sleep with her, but Cody told him, “Not yet.” She set some ground rules. He said that he’d only do things she was comfortable with; he wouldn’t rush her in any way. “So we kissed and kissed for hours. My jaw is tired.”

“Was your mouth closed tight the whole time while you kissed?”

“Yeah.”

I told Cody how proud I was that she set boundaries, and that she did only what she wanted to do with her new boyfriend. “And, I have a tip for you when you kiss him tonight. Relax your lips and let them feel soft.

Part your lips just a little. You can move your lips around some while you're kissing."

Cody called first thing the next morning. "Mom! That kissing tip was the best! It made a big difference. He said I'm the best kisser he's ever had."

Two weeks later her new boyfriend told her he never wanted to leave her. Cody wrote him a letter explaining more details about her disability so that he knew what to expect from her if they became more intimate.

She said, "I thought if I tried to talk to him about it, I'd get flustered and forget what I was saying."

Cody had often asked if I'd ever marry Ernie, and I finally gave her the news she was waiting for. She screamed, "Yay! Now I'll have three dads—like *Three Men and a Little Lady!*"

Ernie and I flew to Las Vegas to be married in December. But while we were gone, Cody suffered a broken heart. Her forty-one-year-old turned out to be "immature." After their two months as a couple, he told her, "I screwed up. I'm sorry. I can't handle commitment." But even as he said this, he told Cody that she was beautiful and repeated that she was the best kisser he'd ever had, and the best sex (despite the fact that their physical interactions had not included intercourse). As Cody described her heart-break, I thought again how the hardest part about being a parent is when the kid hurts, no matter what the reason or how old the kid is.

Despite occasional rejections, Cody remained a hopeful romantic. She told me about every cute guy she liked and provided details about whatever intimacies she experienced. I was her happy girlfriend, enjoying her enthusiasm and commiserating with her disappointments.

Whenever she told Dennis about her boyfriends, he didn't want details. "I don't want to think of some man pawing my daughter."

This gave Cody license to tease him. She took delight in seeing Dennis squirm when she mentioned anything about kissing or sex.

Cody met several young men in chatrooms on the Internet and had fun flirting with them online. Ernie warned Cody about online predators and cautioned her not to reveal her last name, address, or phone number to new online friends.

Irish musicians played violin, mandolin, guitar, and bodhran at our house party in June to celebrate our marriage. My mother greeted guests at the door, and Cody chatted with everyone. Her cousin Joanna sat at the piano with Ernie's nephews. My brother danced with Ernie's sister.

Cody said to Lorraine, "Now you're my new grandmother," and Lorraine smiled, saying, "Yes." Before a Metro Mobility bus took Cody home, she called me into the bedroom. She gave me a charm in the shape of a house and said, "I'm so happy you married Ernie."

She had referred to Ernie as "Mom's boyfriend" for more than two years. Now she called him her stepdad, but introduced us to friends and PCAs as her parents without the "step" part. She made a giant card for him on Father's Day that said she was happy to have him as a dad.

When Cody turned twenty-four in August, a dozen red roses in a cobalt-blue glass vase were delivered to my office at work with the note: "To the greatest mom in the world. Happy 24th Anniversary of the birth of your baby girl! I love you, Cody."

In October, after three years with the same agency, Cody was fed up with unreliable PCAs who left the company, got married, had babies, followed boyfriends out of town, went into chemical dependency treatment, or gave any number of other reasons for leaving after a few days or weeks. Some new health problems made reliable help from PCAs more essential. I joined Cody when the nurse from the new agency came to interview her. Cody described a typical day and included her health issues.

As she'd done since childhood, Cody rolled out of bed in the morning and sat on the floor to cath herself. She lifted sideways on her right hip to push down to empty her bowels. Her stool was usually firm and came out in tidy manageable pieces. After emptying her bowels as best she could, she used moist wipes, then wrapped the incontinent brief for disposal. She scooted into the bathroom where she sat on the floor to take her morning shower.

Antibiotics were prescribed every few weeks due to more frequent urinary tract infections. Cody recognized a UTI by a sudden strong smell from her urine or an otherwise unexplained fever. Because Cody often coughed hard and gasped with colds, asthma had been added to her

medical summary. More antibiotics were prescribed a few times a year for this. Refusing allergy medication that made her drowsy or dizzy, she instead found an over-the-counter alternative to use along with her inhaler.

The agency nurse noticed that Cody's ankles and feet were swollen. This was something new. Her primary care doctor thought it was due to poor circulation. He had advised Cody to elevate her legs for part of each day. She had discovered pressure sores on the heels of both feet that now required daily wound care. After the nurse left I read the care plan summary:

PCA to assist with Activities of Daily Living: Make meals, refrigerate for Cody to warm up. She needs to eat healthy foods high in protein to promote healing of ulcers. PCA to help with dressing if Cody is ill. Cody does her own bathing, shampooing, showering, and drying. Cody refuses help with peri care. Some movement difficulty due to weight and edema. Using Keflex, Proventil puffs, Claritin as needed. Allergy to cold. Gets on floor in shower. Hours: 10-1 , 4-6.

PCAs from the new agency were more reliable; Cody was rarely stranded. She called me less often as she became more involved with online friends and the occasional new love interest. I heard from her only once a day and our conversations were shorter. I took this as a healthy indication that she had a life, and she was busy living it.

Ernie and I stopped by her place a couple of times a week. Cody played her favorite new songs for us and introduced us to new PCAs or someone she was dating. We met Jake, who had cerebral palsy. He had an accessible wheelchair van, which meant they could go places together. The relationship involved a lot of laughing, from what I could tell. Jake had his attendant take pictures of him reclining naked in various poses as a gift for Cody. One afternoon, Cody giggled and showed me the pictures. Ernie was busy checking expiration dates and throwing away outdated food from Cody's refrigerator. I winked to Cody as I handed the pictures to Ernie.

Ernie, distracted by his project when he took the stack of pictures, glanced at the photos in his hands, recoiled with a start, and said, "Whoa. I didn't need to see this."

Cody dissolved into laughter. Ernie said, “Jake probably didn’t intend for you to show these to anyone.”

With a wide smile Cody said, “Why not? He looks pretty good, don’t you think?” She collapsed laughing again.

Cody exchanged emails for some time with Frank from Wisconsin. He drove three hours to meet her. She made sure she had a friend present the first time he came. Frank was a sweet guy, attentive, and offered to help with some of her personal cares. But after a few trips, Cody discouraged him from further visits. He called on and off for the next year asking to come back, but Cody was firm in her view that she and Frank had no future.

Cody had a romantic date with a man she’d known for a few years. Matt was in an electric-powered wheelchair. Instead of breathing through his nose and mouth, he had a tracheostomy tube that went into his windpipe through an opening in his throat. He and Cody were solid friends with an attraction that they finally acted upon one night. They kissed with enthusiasm and, without realizing it, Cody yanked out his breathing tube. Matt wasn’t disturbed by this accident; he simply called his attendant in from the next room to replace the tube. He was fine, but Cody was horrified. She told Matt she was sorry but they couldn’t continue an intimate relationship. He tried to convince her otherwise, but she was definite about it.

She told me, “I could have *killed* him!”

I said, “It sounds like it was no big deal for him. You don’t want a minor accident to keep you from someone you really care about, right?”

“No way, Mom! I’m too scared I’d hurt him.”