

Chapter One

Hazel Straughn and Edward (Casey)

My son, Edward, was born January 25, 1980, with just one additional chromosome – he has Down syndrome. I was caught unaware and pushed into this frightening unknown. First, you ask yourself, “Why?” Then you think, “Never in God’s world am I going to be able to handle this.”

The News

In the summer of 1979, I didn’t even know I was pregnant. I was 41 years old, soon to be 42 in December. I had stopped going to Dr. Casey, my OBGYN. However, I began having a few problems and missed a period. When Dr. Casey heard this, he said, “Oh, well, we’ll see how you go. Maybe we’ll do a lower GI test to see if something is wrong, but this is not alarming. You may be just starting ‘the change.’” “Okay,” I said.

Soon after, I was on the tennis courts and said to a friend, “You know, I think I’m pregnant. My legs are like cement. I have energy, but I am so heavy feeling.” I called Dr. Casey that afternoon on my way to a swim meet for my daughter, Carolyn. He told me to bring in a urine sample and said, “I will know by 5 pm if it is positive.”

All afternoon, every chance I got, I was out at the pay phone; I was even calling the office between the swim meet races, ones I was supposed to be timing. I got nowhere. Finally, I reached an operator and pleaded, “I am running out of dimes. I am trying to get my doctor for test results.” She put the call through and Dr. Casey answered, saying, “You are 100 percent pregnant.” “Oh my God,” was my only answer. I thought it would be *my* time now that my two children, Bill (12)

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and Carolyn (10 going on 11) were in school. I had intended to get a job that fall at, of all places, Cardinal Cushing School.*

Looking back to that year, 1979, I was physically and mentally healthy; I couldn't get more fit – playing tennis every day from May until October. I only gained 17 pounds throughout my pregnancy. Early on, the doctor did mention having an amniocentesis test, but the results would have taken two to three weeks and by then I would have begun to feel life. I quickly dismissed the thought of getting the test and nobody – friends or family – thought anything about this pregnancy despite my age. Down syndrome or any other disability was not on our radar. I joked that this baby was going to be my doctor or my lawyer. My husband, Harry, was teased by friends and renamed “the stud.”

After keeping my pregnancy a secret for a month or so, I finally told my children and, with much excitement, they shouted that they wanted twins – one each. That same day, as scheduled, we went to the Swim and Tennis Club and both Bill and Carolyn ran to tell the news to their swimming instructor. She, in turn, went on the loudspeaker and announced, “Mrs. Straughn is in a family way.” Kids were going home that night saying, “Mrs. Straughn is in a family way. What does that mean?”

We were typically at this club all day in the summer, from nine in the morning until ten at night. After arriving one day, I put our bags and towels on a table and looked down. Blood! I grabbed a big beach towel and went to the phone booth to call Dr. Casey. I told him I was hemorrhaging, and he said, “Get to St. Margaret’s. I will head over.” I called Harry to tell him to meet me there.

Without even knowing the directions to the hospital, I went off with another mom, leaving Bill and Carolyn with a friend. We ended up lost in Boston’s Chinatown. Finally, we stopped a police car. The policeman came over and looked in the window only to see the seat – and me – laden with bloody towels.

*Cardinal Cushing is a living community and school begun by Richard Cardinal Cushing in 1947 for 35 “exceptional” students. Today, students from ages six to 18 are schooled in functional academics as well as daily living, vocational and recreational skills.

“We’re trying to get to St. Margaret’s,” I cried, “but we’re hitting all one-way streets and I’m hemorrhaging.” “Follow me,” he said, and away we went, with sirens blaring. After an examination in the ER, I

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was admitted and stayed overnight, as this was the critical three-month mark. A nurse came in and asked me how I would feel if I lost it. I said, “What will be, will be. I have no control over this.” Everything stayed intact; I was free to go home, and the doctor told me that I would give birth on February 20 – Harry’s and my fifteenth wedding anniversary.

Summer turned to fall and soon winter came along. Suddenly, in January, my water broke. Dr. Casey told me to keep my feet up and put towels underneath me; he wanted to keep me from delivering the baby for as long as possible. He explained that no harm was being done to the baby, and that I would be okay unless I ran a temperature. I finally went to St. Margaret’s on a Tuesday but went home two days later, after my kids called Dr. Casey to tell him a surprise baby shower – which I couldn’t miss! – was planned for that Thursday night. I managed the baby shower sitting on towels. We laughed and carried on. Friday, as I was getting the kids ready to go to school, I started shivering, really shivering. I thought I must have a temperature and called the doctor to be safe. “Get the kids taken care of and come on in,” he said. Harry, who was already at work, came home, drove me to the hospital and then left for a basketball game. I was alone, except for the nurses monitoring my contractions.

The Birth

This was unlike either of my other two pregnancies. With those, I went through labor easily, but this experience had me go through waves of contractions. Finally, at 10:30 pm they called Dr. Casey, who came in to examine me, gave me a spinal and told me not to push...just “breathe like a dog.” I can still hear myself panting, and in between saying, “I prooomiz...I ammmmm Nooooot Puuuushhhhhing.” Finally, at five minutes to midnight, out came this little baby. I had already told Dr. Casey that I wanted a girl – and I did not want a redhead. When my baby was delivered, Dr. Casey said, “Oh my God, it’s a redhead...Oh my God, it’s a boy.” Right away, this little guy was whisked off to the ICU. I never really saw him; the only thing I happened to see was a little slanted eye.

A resident came into my room shortly after I delivered. I was alone, not knowing anything about my own newborn. He said, “Your son is a mongoloid.” I looked at him in disbelief. He was stern and said emphatically to me, “Say it, say it.” And I finally muttered, “Mongoloid.”

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Dr. Casey came in shortly after that, and he and I cried together; just he and I. Harry came in that night, after midnight, despite my protesting, “This is nothing special, it’s no biggie. Just stay there with the other two.” After peering into the ICU, Harry said to me, “I saw a halo around him. He’s special.” That was so unlike my husband – I had to take it in.

The next few weeks were hell. I stayed in the hospital for a week, fielding questions from doctors, nurses and social workers. I had nothing to say. At that time, they institutionalized people with Down syndrome; I was given that option. One of the nurses told me that they didn’t have to put him in an institution; they could put him up for foster care. She went on to tell me that I did not have to bring him home, no questions asked. I was shocked. Of course, I would bring him home.

I missed meals just to be down in the ICU, where I could sit and stroke his hand. I couldn’t hold him, I couldn’t feed him, and I couldn’t yet take him home. I just talked to him. Even before I named him, I noticed that the sign on his incubator said, “Baby’s Name: (Edward Casey) Straughn; Doctor: Edward S. Casey.” After asking permission, we named him Edward, but have called him Casey forever.

When Edward was two weeks, he had to be seen by a pediatric cardiologist, Dr. Feingold, who needed to investigate what was apparently a slight heart murmur. He found nothing to indicate anything abnormal, except for a slightly slanted eye. He said, “I don’t want to say anything definitive about him, and don’t you, until these blood tests come back.” We had two to three weeks more to wait; I was a basket case and felt like I looked 92. There were many, many nights I cried myself to sleep. The test results finally came back and, yes, Edward had Down syndrome.

Edward was not floppy like most Down syndrome babies, and his sucking reflex was good. However, he had a lung infection, he was blue, he weighed five pounds and was five weeks early. Because of his infection, they treated him with antibiotics intravenously through his head, and protected the spot they had to shave with a cup – placed on his head like a crown. When my sister came in and saw it, she immediately called him “King Casey.” She even went so far as to get a t-shirt made for him that said, “I am the King.”

After he was home, and I had the freedom to touch him, this whole thing finally became a reality. I thought, “I will handle what I have to handle,” but truthfully, I didn’t know anything. At night I would be

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downstairs where my children couldn't hear me, hysterically crying to the point of not being able to catch my breath. "Why me?" I'd ask, "What have I done?"

I was also in and out of fits of anger – angry that this happened to him...and to my other two children. His disability would put such a responsibility on them; I worried how much Edward would interfere with their lives.

Acceptance

I was so, so scared for a very long time. With friends, I used to joke and say, "I tried to put him back, but he didn't fit." I found that – in order to cope – you joke a lot and you lie a lot.

I am not one who sits in church, but I do have "Holy Mother Mary" icons around the house for comfort. It was at Easter time, the year he was born, around two in the morning. I was feeding him and lost in my own world, just thinking. All of a sudden, I felt this sharp pain, a very sharp pain in my back; it was excruciating. Strange, but at that moment I thought, "The Holy Mother knows this pain," and "this is what will help me get through it." Instantly, I understood it's not what you can *handle*; it's what you have to *do*. I made the decision then and there – "He's going to make it." The pain subsided, and I have never felt it since.

Early on, I went to a parent group and when I got there I found that the others were all professionals: nurses, pediatric doctors, etc. They knew before they gave birth that they were having babies with special needs. I noticed that Edward was the only one crawling; the others were held close to the parents' chests like precious rag dolls. A few group members said to me, "I wouldn't want my child any other way." Amazed, I replied, "You've got to be kidding me. I would give my arms and legs at this moment to have him be a regular kid." I never went back to that group. I did, however, speak to my pediatrician. "Is there something wrong with me? These parents are going to be psychiatrists. I don't have time. Is there something the matter with me?" "No," he said, "you've accepted the fact." I was satisfied and decided therapy was not for me. That parent group was the extent of "services" offered at the time. There were no programs or people knocking on my door wondering how I was managing.

Our town was a very small place then, and news traveled like wildfire when Edward was born. Bill and Carolyn were also in the local

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school system, so all their teachers knew. Along the way, I would have teachers and well-intentioned people say, “You should do such and such.” Nine out of ten of them never had kids, much less a kid with special needs. I was getting advice from everyone, and as much as I was grasping for ideas, I would take what advice I thought I could use. The more I talked to people and the more I heard myself use the words Down syndrome, the more I began to accept it.

I was on a mission, as most parents are, but this was different. You go along day by day and do what you can do. I would say to Bill and Carolyn, “He’s going to reach for a star, and we’re going to push him to it.” I didn’t know what he could do because I had never been here before. When the light goes on for him, that’s what you take. And it does come on.

As for my older children, their lives went on. Before Edward was even born, Carolyn volunteered in an after-school program with students from the Paul A. Dever School, then a school in Dorchester for children with developmental disabilities. These kids were tough; they were explosive. They bit her and threw things, but she grew to understand them. My son, Bill, had a much harder time accepting Edward in his life. It wasn’t until he went to college at Northeastern University that he could even say to me, “I love Edward.” Edward and he are not only brothers now, they are true friends; the same holds true for his sister, Carolyn.

Milestones

Edward wasn’t walking when my other children did, so I found a physical therapist, Mary, when he was a year old. I brought Edward to her home for therapy. To set up for one of these sessions, she and I rearranged furniture; taking the cushions off sofas and chairs, and pulling out tumbling mats, balloons, nerf balls – you name it. We worked on everything: following directions, muscle tone, mobility, coordination, even articulation. Together, we addressed different problems as they arose. The activities we did were all those that a regular child would do, only we did it in smaller steps – slow motion, you might say. “Go get me the banana on the couch.” He would have to crawl, not walk as others his age might. He would get to the cushion, climb onto that, crawl up to the couch, climb up onto another cushion, get the banana and then bring it back to me, telling me the word for what he had in his hand. There were two things I was learning in this process: first,

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I had to make learning playful, and second, I had to plan every move. Just think about what goes into standing up from a chair. Most people would say you simply have to put your feet on the floor and lift, but actually, you bend forward first, and then put your hands on your lap or on the side of the chair. I had to be clear about how to do whatever it was I asked him to do, step by teeny step.

The other thing I remember was his first steps. He walked at 18 months, but he shuffled his feet, never lifting them. I had to teach him to place his heel down first, then his toes. We sang, “Heel-toe, heel-toe” and marched around and around the living room. To improve his muscle tone, we put a bar in one of our doorways and had him do pull-ups and chin-ups. Sure enough, we had to do it with him, too. Thank goodness Carolyn and Bill were teenagers, so I was occasionally relieved of “chin-up duty.”

Carolyn and Bill would go to their friends’ houses, but sadly, they did not bring friends to our house. When they *were* with Edward, however, they were very attentive. Edward was a toy to both of them, one they loved to have fun with. They swam with him, read to him, and played with him frequently.

I would get so gassed up seeing Edward catch on and learn a certain thing. When he finally began walking, we played a game called “The little old lady from Italy.” Naturally, I played the little old lady, donning a scarf on my head and talking slowly with an Italian accent. I would send Edward into the living room to pick me up a *meat-a-balla, a loaf-a-bread and a glass-a-milk*. He loved these skits and joined in the make-believe stories. In the spirit of play, Edward learned to imitate all sorts of characters I would make up. Little did I know that these performances were important for what later developed: a keen understanding of adventure, an intrigue with accents, a vivid imagination and a love of books, which still serves him well.

Speech

Edward’s memory was getting a good workout, but his speech concerned me. I remember asking a doctor friend of ours, “Where is the vocal part of the brain? Why isn’t he talking? He has got to talk! He can’t make it if he doesn’t talk.” “He will be fine,” the doctor said. “It’s just going to be a very, very slow process.

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I didn't want to wait. For a long time, we sat on the floor in front of a mirror with him between my legs. I could see that the whole structure of his mouth needed to move more, and his ability to form words needed to be developed. We started with all sorts of tongue exercises and sang in front of that mirror every day. Actually, we babbled: "La la la la and Beh Beh Beh Beh." We would continue in the car with whatever we were practicing at home: singing our ABC songs, nursery rhymes or songs I remembered teaching my other two, such as "Put One Foot in Front of the Other." Everything we did, whenever we could, was singsong. He began to get it! When he did start talking, at age three or later, telling him to be quiet was not allowed in our house. I told my family to just let him go and when he makes a mistake, correct it on the spot.

To build on this, we took him to Children's Hospital for speech therapy when he was just over a year old. (He loved playing on the elevators and always knew which floor we were going to.) After a number of speech sessions, the staff said there was nothing more they could do for him. He had progressed so much because Carolyn had played many similar board games with him, ones that she made at her volunteer job for students at the Dever School. She brought them home each night and we would sing the directions to him, "Put the pole in the hole..." He had a good attention span, as long as we kept it fun.

As he was learning to socialize, I would tell him, "Don't say 'I am fine,' say 'I am fine and how are you?'" I would again play act. While walking around the living room, all of a sudden I'd turn around and ask, "How are you?" And I waited for his full response. I had to learn to do everything in slow motion; one step at a time, one word at a time, one concept at a time. Constant talking and frequent repeating worked.

We never labeled things in the house. I insisted that if he wanted something, say to drink, he would have to come to me and say the word, "drink." He would repeat it until he said it correctly. I made it clear that he was to use his words with everyone. Whenever he wanted to give up, he was told, "Don't say, 'I can't,' say, 'I'll try.'"

I went to the special education director when Edward was two-and-a-half and asked to enroll Edward in the town's preschool program for children with special needs. (He was potty-trained at two, so I thought he was ready.) At that time a child had to be three but the director said that he could start if I drove him back and forth every day until his birthday. So, from September to January I drove, and after that

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he was allowed to take the bus. On that exciting, landmark day he popped out of bed and waited eagerly at our back door for his first bus ride.

At one point, early on, I went into his classroom and the teacher began, "This is the signal to go to the bathroom." Immediately, I said, "No, I don't want sign language. I don't want a crutch for him. When he has to go the bathroom at home he will tell me." People seemed to push for sign language then, but I did not want it. Fortunately they listened, and he never had to learn to sign.

First Love – Reading

Having an adolescent boy and girl meant my children were never at the same place at the same time. They were on swim teams and in other sports in town. I had made a commitment to myself that Edward was not going to interfere with their lives. He had to learn to go with the flow, so he got used to eating in the car and going wherever and whenever my others had to go. I always carried a bag of audio tapes; he loved to listen to the Disney stories and would *read* along with them. He got to the point where he could follow the words and turn the page correctly when the tape beeped. He also learned to find the right tape for the right book. I remember one person who, seeing him so captivated, came over to me and said, "You're so lucky he's reading." I had to be honest and replied, "No, he's got it memorized." Wherever we went, the other teenagers were great with Edward. He would go from one to another, and when he got tired of one he would find someone else. They would read to him, talk to him, or play with him. He was never just plopped down somewhere; he was an active part of everyone's life. He learned about other people's feelings and emotions – and I hope they learned from him.

Edward never tired of engaging, and books would keep him occupied for hours. We read constantly in our house. When he was very young, I read to him all the time, stories like *The Night Before Christmas*. I would use my hands to indicate the snow was falling, pinch my cheeks for St. Nick's rosy cheeks, and I would click-clack like the reindeer on the roof. Later, when he'd hear any of the stories, Edward performed every gesture he had seen me do. To this day, he is an astute observer and a great imitator, with a memory like steel.

His elementary school started a mega-books series, which I used as his treat at night, as well as his punishment. He *loved* to be read to,

but if he hadn't done his homework, picked up his room, or gotten his clothes ready for school, I wouldn't read. I also noticed that so many people indulged Edward and he was starting to get smart with me, so if he was fresh or gave me mouth, I wouldn't read.

As he got older he loved series books, especially *The Hardy Boys*. I would read him a chapter every night. There are 63 books in that series; we read them all at least three times. *Harry Potter* series? Same thing. He knows all the characters and each story. He was so sharp that if I made a mistake reading he'd correct me. These books are still on the shelf in his room – even when I try to help him clean things out, those books don't go anywhere. Just recently he asked me to reread *The Hardy Boys* with him.

Early Life Lessons

Edward knew who he liked and didn't like, and made no bones about showing his dislike. In grammar school, a notebook went back and forth between his teacher and me. One day, she reported: "Today at recess, Edward decided to bang two boys' heads together. I spoke with all three boys but could not come to any reason for this. Edward spoke up, saying 'I just don't like them.'"

Another excerpt from this notebook read: "Today at recess I had to ask Edward to stand by himself at the wall. He had gone up to a boy in the schoolyard and told him to move out of his way. Then, as he walked by, he pushed his classmate down. The boy bounced when he hit the ground. I was concerned about this because he landed only about an inch from the pole of the swings. I reprimanded Edward and he seemed to understand." He needed to learn how to get what he needed or wanted without such physicality!

People, for some reason, loved to feed Edward, constantly. It got to the point where I had to tell well-intentioned people that the doctor put him on a strict diet, otherwise he would be eating all the wrong things. Edward will pick up bad habits quickly. It is easier to learn the bad ones than the good ones, so all bad habits must be stopped immediately. I told most everyone to be strict with him because "give him an inch, he'll take a mile."

Some bad habits were scary. In department stores, he would romp around and then hide underneath a rack of clothes. If there were drawers, he would pull one out and climb in, leaving me searching. One day at our local supermarket, Edward went into the men's room without

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telling me. As I searched for him, the store went into lockdown and the manager called his name over the intercom. People in the parking lot, many of whom knew Edward, heard the reason for the lockdown and began to holler his name. Suddenly, Edward came sauntering out of the men's room. We learned then that the intercom didn't reach the bathrooms, so he didn't even know we were looking for him. Such fear never leaves me. I decided to try to show him how scary going missing is, so I reversed the scenario and he now knows that hollow feeling of losing me. Even today, he remembers and doesn't let me out of his sight. He has called me over the intercom in all sorts of stores. I could be in the next aisle of the grocery store, but if he can't find me he'll go immediately to the service desk and have me summoned. He has had me paged at the mall, too. I used to take him there and let him go from one store to the next on his own, always knowing where he was and memorizing what he had on for clothes. One time, he went into one store and I walked down to the next store, as I always did. Suddenly, I heard a loud male voice say, "Hazel Straughn, please report to the security desk." Edward somehow didn't see me right outside *his* store, so he went to the security police and told them that I was missing. He uses common sense when he has that sick feeling, so I guess my experiment worked.

Edward has some common sense but his ability to judge new situations is often skewed. Once, a different bus driver met him at school to take him home. He did not get on the bus despite the driver telling him that she was there for him. When he got home, he said, "I did not know that van driver, so I walked straight home."

His common sense is one thing, but he also just doesn't know when to keep his mouth shut. And I learned that the hard way! A doctor's wife was at the Swim and Tennis Club. A large woman, she eyed a lounge chair to plunk down on. As she neared it, Edward cried out, "Oh, no, you're too fat. You'll break it." There is no filter. And P.S. Never tell him that something is a secret; he will quickly spread the news all over the place.

As Edward matured, I set very strict parameters and made it clear that he could do what was acceptable within those guidelines. I never spanked Edward, but had to find effective ways to punish him, when necessary. If he had an attitude or a nasty tone in his voice, I would tell him to go the bathroom and wash his face until it was gone. Most of what I tried worked, but I relied simply on instinct; I really didn't know

what I was doing. You come to do things on the spur of the moment – it's not written anywhere. Sometimes you wonder if you did the right thing, and then you agonize. I wouldn't wish this on my worst enemy, but then again, I don't know what my life would have been without him.

Second Love – Swimming and Medals

Edward really grew up at the Swim and Tennis Club because of our commitment there with our two other children. One of the swimming instructors, Fran, would take Edward into the pool and work with him during "Adult Swim" time. He was swimming, thanks to her, when he was five months old. Other club members became interested in him, and he easily went from person to person; he was not special needs in that setting. He never wore a life jacket, and as he got a bit older he would walk around the pool alone. I would respond to people who questioned this by saying, "He knows where his body is; if he falls, he falls. He will have to go down three times before he learns. There are plenty of eyes on him here; he'll be okay." In the neighborhood or elsewhere, whenever Edward did fall, I would say to him, "Don't bleed! Blood stains! Get up and shake yourself off."

Edward was only five or six when he was recruited to participate in Special Olympics. That's a year or two ahead of most athletes. We went to Bridgewater State College for their tryouts, and he came in fourth. In the official, grand style of the Olympics, they announced the names of the winners and had them stand on platforms to receive the gold, silver and bronze medals. It was then time for Edward to receive his fourth-place ribbon. He took it, saying, "Thanks, but I only go for the gold," and promptly threw the ribbon into the wastebasket!

He participated in Track and Field when he was seven and did okay, but Edward's legs have never been an asset; his power is all in his upper body. At that same time, I brought him up to a fitness center to swim and one coach, Kathy, took an interest in him. She had a pool in her backyard and suggested we go there for lessons – and did he learn. She taught him Freestyle, Breaststroke, Backstroke and Butterfly. For years, he swam with regular kids on various South Shore teams, and for ten years he swam with four other special needs kids who called themselves the Sharks – all before he was 16. Edward's forte was Free-style and Breaststroke. Over time, the Sharks – Gerald, Artie, Christian

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and Edward – were top relay swimmers. They had no competition and swam against the clock.

A group of us parents would host parties and fundraisers for the Sharks. We held a banquet at the Swim and Tennis Club once and raised money to buy Special Olympic sweat suits for the team. Another time, when Edward was nine or ten, we raised enough money to send his whole class and their teachers to Disney World for four or five days. The group took a limo to the airport and then, given a head's up, Jim Green, the “sky high patrol” pilot for Boston traffic announced, “There goes the limo taking the special needs kids to Disney, toot as you go by.” Everyone had a ball.

The Sharks continued to do well and went on to swim for the championship. A teammate, Artie, was to swim last. His sister knelt at the side of the pool and whispered her sage advice. “Don’t you dare breathe ‘til you get out.” Finally, when he surfaced, he asked, “Can I breathe now?” They were victorious, beating the national team by a full 25 meters, and were nominated to go on to the Nationals.

Edward swam four or five days a week through middle school. At one of the last get-togethers, when Edward was 15 or 16, his swim mate, Christian, decided to give up Special Olympics and, because they were a relay team, Edward decided to do the same. To this day, when asked about swimming, he says, “Nope, I’m retired.”

Medical Traumas and Game Changers

I learned early on that when a child with Down syndrome gets sick, the infection travels fast. My primary care doctor gave me a valuable tip. “When you call any doctor’s office, tell them that Edward has Down syndrome and they will get you in the back door. They know that this population needs attention quickly. Even if it’s just a cold, they just can’t say “take two Tylenol and call me in the morning.” To this day, I still follow that advice.

Edward had terrible stomach aches in grammar school. He would have explosive, often unexpected bowel movements. There were times I would be cleaning toilets at the mall, throwing away his clothes and buying new ones on the spot. It came to the point where he was drinking full containers of Metamucil every day. My hunt for a diagnosis was exasperating. One doctor told me to bring in bowel specimens and then sent me off saying Edward just had an intestinal bug. But something was clearly wrong. His stomach would expand – literally rise way

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up – and then he'd shout, "Mom, I gotta go, I gotta go." He would burst with stool, black stool. Carolyn and I finally brought him into Children's Hospital. They sedated him and did a multitude of tests, even taking a biopsy of his intestine. Their diagnosis? 100 percent lactose intolerant. That is when we began Fiber Com and quit all dairy products.

I still give him Lactaid milk and he checks with me all the time if a new food is in the offering. He will simply forego eating if he is not sure or if he knows he hasn't had a lactose pill. Before all of this he ate most everything; now he is extremely cautious. Even I have made mistakes in my choices of food for him, which has made him even more leery of trying new things so he sticks to safe foods. Five mornings a week, before school – or now work – Edward has a bowl of Reese's Puffs, 9 ounces of Lactaid milk, some juice and, after he showers, a Diet Coke while he watches his show on TV. On weekends, he will have a bagel, bacon, juice, milk and, of course, his caffeine – a Diet Coke. For lunch every day, Edward has a dinner roll, 4 pieces of thinly sliced bologna, a bag of chips, a banana, and a container of sugar-free lemonade. Every night he has two low-sodium hot dogs with ketchup, a large, no-salt, soft pretzel and a mug of his Lactaid milk. Later, he'll call out for his snack – a sugar-free ice cream sandwich. He eats less than he used to and never eats between meals.

As a youngster, Edward didn't eat soft foods; he always had to have things that were hard and crunchy. He is now eating salads here and there, consisting of raw green beans, cucumbers, lettuce and celery. We tried carrots, but he once got a few bitter ones, so they were out. It has taken years, but I finally have a variety of foods to feed him: cans of lite fruit, sugar-free ice cream, pretzels, Fudgicles, Klondike bars, sugar-free Jell-O, and pudding. His diet is much better than it was, but it's boring, and odd.

Going out to eat is a challenge. Once, a group of us went to a restaurant on the water in a summer community. I asked for a hot dog for Edward and they said they didn't have any – only hamburgers. I had to get in the car, drive to the grocery store around the corner and buy a package of bologna and a bag of pretzels. "I am sorry," I said to the waitress when I returned, "but you don't want me to sue you; he is allergic to what's on the menu."

When Edward was young, doctors would automatically test his urine for sugar. It's always been on the high end, but I thought it was

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because he had usually just eaten something prior to the appointment. When he got to high school, however, the school nurse mentioned that he was cramping up, drinking a lot and always going to the bathroom. There were reports that he was also sleeping all the time on the van going back and forth from home, out to worksites and even on field trips. He was also moody in class and seemed generally disinterested.

I tried to piece together timely incidents that I thought might have influenced this. For one, his good friend from the gym had a seizure on the basketball court and died in front of him. It was very, very emotional. That year, there was also a bad flu season and Edward was hit by it. And lastly, I attributed these mood swings and the little he did complain about to his sleepiness. We finally took him to a psychiatrist to evaluate his moodiness and low energy. After an hour with him, the doctor said, “There’s nothing wrong with this kid.”

It was hard to sort through, but his symptoms, including stomachaches, frequent urination, insatiable thirst, tiredness, dizziness and complaining that he couldn’t see, did not get better. At a routine appointment at Children’s Hospital, the doctors were alarmed to discover he had dropped 35 pounds – pounds nobody noticed because of the baggy sweatpants he wore at home and to school. They ran blood tests and told us they’d call with results in two days but phoned just 24 hours later. “He has diabetes,” they said. They told me later that I could have lost him.

Edward was admitted into the hospital for a few days and was put on intravenous insulin; I slept in the chair in his room. A personality clash got in the way of his treatment there, so we headed to the Joslin Diabetes Center in Boston. Even though he was 20, we went to a pediatric unit where all insulin was premixed. We learned about diabetes quickly. Edward was taught to do his own testing; I would do the mixing. From the beginning, we have kept a running list of his sugar levels, five times a day, if not more. People with Down syndrome have a tendency toward diabetes, but in Edward’s case it is inherited from his father’s family.

What does this mean? It means I can’t send him for four or five hours anywhere. I can’t have people take him to a movie because he shouldn’t sit that long. Unless I go along, everyone is afraid he’ll have an episode of going high or low. Being sedentary will drive his sugar levels up; too active, he’ll go low. That’s why I travel with all sorts of snacks. Water is a constant, it’s a filler, and walking is the best thing

for him. However, nothing is a sure bet. He can go to the gym at 3 pm, work out, and have high sugar levels at 5 pm. There are no two people the same, and there is no telling day to day what will happen. That makes most people uncomfortable.

The good news is that Edward knows what to do; however, he needs constant reassurance. He carries sugar tablets in his apron every day to work; he has candy in his lunch bag and his tester is always on him. He might call me after he eats lunch to tell me he's low. Calmly, I ask if he's had lunch and eaten his banana. If he has, I tell him he's okay. He needs to know that he did the right thing. I still wait until noon every day to know if he is all right before I can be relieved from running to his work to give him a shot.

Edward is comfortable with me because it's always been the two of us managing this. When Edward was in the hospital, newly diagnosed with diabetes, Harry wondered why I was staying in there with him. What he really wondered was "Who is going to take care of me?" Later, when the visiting nurse came to teach us how to do Edward's insulin, she called out, "Well, come on out here Harry, so you can learn." Harry replied, "Oh no, I'll do what I have to do when I have to do it." To this day, 18 years later, he has never learned nor helped with any of Edward's diabetes issues. He doesn't bother to know his diet, his schedule or his routines; he's just here.

I make a point to educate Edward's drivers, his managers at work and the staff at the gym about Edward's diabetes and what he is capable of doing independently. I am adamant that he eats the food I pack every day, and that he exercises at the health club most days.

Edward has been at this gym, Health Fit, for some time. Originally, when he was swimming there, they gave him a locker and a lock. He would put some clothes in one locker and some in another, and then he would misplace the key. "I need your help!" he would shout from the locker room. They cut off more locks until they finally decided that his gym bag would be better off left at the front desk. And, despite the changes in management, Edward's clothes remain behind that desk.

With the diagnosis of diabetes, staff at Health Fit put him on the treadmill for a certain amount of time and then onto circuit machines. In the beginning, they printed out his program and I would take it to the Joslin Center where they reviewed it and either said, "Fabulous, keep it up," or adjusted it. He tests himself the minute he gets to the gym. If his sugar is high he is told immediately to go walk it off; if he

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is low they give him orange juice or candy. Then he calls me. “I’m low, Mom.” I just say, “Okay.” I have complete peace of mind when he’s at the gym. His work place offers the same comfort. If his sugar was low at 7 am, I know what he will be eating and, therefore, I know he will be in good shape. If they call me worried, I tell them he is fine, just fine. I am that confident.

I can open the door to Health Fit and instantly know what machine he is on because I can hear him singing. I have told the staff that if he gets too loud, tell him to pipe down. “Oh no,” they say, “it puts a smile on our face!” Edward is hooked on watching General Hospital at 3 pm, and one of the other people at the gym likes watching the Food Network while he’s working out around the same time. The two of them were always trying to get there first to put on their show. The health club realized this and now they schedule one show on one channel, and the other show on another. Both now walk the treadmill happily!

School Trials

It was at Health Fit that I met a math teacher from a Vo-Tech (vocational-technical school) who put new hope in our lives. He encouraged me several times to put an application in for Edward, telling me, “Edward’s got the ability to do this. I will speak up for him.” In those days, some of the students at the Vo-Tech were not the brightest academically, but they could all read and write; Edward could not. The Vo-Tech had an advertisement that said, “We don’t discriminate against special needs.” I thought, okay, we will try. We took it to the next level and met with both his middle school special education teacher and the town’s special education director. We hired a lawyer affiliated with the Department of Developmental Services because Edward was the first “handicapped” person applying for placement at the school. Our attorney encouraged us, saying, “This would be breaking ground for those who could handle it.” I was thrilled; Edward would be learning a trade!

To make this work, three parameters were established: Edward would be tried in various vocational settings in the school; the town would hire an aide to be with him at all times; and his previous middle school teacher would supply the appropriate academic materials. Edward was so enthused to start in September, and after opening day things went along okay for a while. Soon, however, the administrators began putting stipulations in place. For example, I was restricted in my

interactions with his aide and his teachers. I was not allowed to talk to them one-on-one; all discussions had to happen with Edward’s “team,” which included his teachers, his aide, the principal and the special education director.

Rules were strict for Edward too. He rode the Vo-Tech school bus, but when he disembarked he was told to sit on a bench at the entrance and wait for his aide to get him. Rules like this made him feel like an oddity. Unlike all the other students, Edward could not go to his locker or walk the hall on his own. All that training in independence from his grammar and middle school years was for naught. Further, it was decided that if Edward’s aide called in sick, the school would call me and Edward could not go to school that day. Many of his rights were violated.

Academic classes suffered as well. Math consisted of being handed colored paper clips to count; and teachers or his aide would read to him instead of having him continue to learn to read. They did not invest any time to make this work.

He came home one day and told me that he had detention. When I asked why, he said, “They were calling me names on the bus, so I went to the office and told them.” “Well, that’s high school stuff,” I replied, “You’ll have to get used to it.” His detention, I later learned, was because he caught onto those not-so-nice words and used them to retaliate against his bus mates. He also figured out a hand “sign language” and became proficient at when to use it. Kids were always turning him in for that. I got a call another time and was told that he had been in the men’s room rubbing feces all over everything, including the walls. Through the aide, I learned that incident was not done by Edward. A lot of hazing was going on; staff and kids were turning everything around to implicate him.

Teachers and administrators simply did not want him there. The Vo-Tech put him in Culinary Arts, but instead of varying his jobs they stuck Edward at the sink alone, cleaning huge pots and pans using scalding hot water. Usually, two students were assigned to this job and they would rotate cleaning and drying. Not when Edward came. He was segregated, included but not included – pure discrimination!

The pace was just too much for him; he couldn’t keep up, but he kept quiet – never a word to me. The aide would call me at night and let me know the truth of what was going on.

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At this same juncture, I was trying to plan for Carolyn's wedding. The chaos around preparing for her big event and managing Edward's schooling, especially given my inability to talk to any teacher when incidents came up, became too much. When there were meetings, there were no positive reports. The "team" made you think that they knew better, they evaluated things better, and they were in charge – period. Slowly, they were trying to get him out of there, and even began telling me that they didn't have the facilities or the staff for someone like Edward.

It was a hell zone for me from September until April, but after spring vacation I said, "Enough," and called the school to tell them he would not be back. I don't remember any of Carolyn's wedding in May. I was in a size five dress, down to 129 pounds. I was having a nervous breakdown and I was anorexic. Shortly thereafter, Edward said to me, "Thanks for taking me out of there, Mom." In all those months, I never heard, "I don't want to go to school." Never. It was hard on him, but he didn't show it. We thought that if he could make it through the Vo-Tech, it would be an important breakthrough and would give another child with a disability the chance to attend. It might even have opened the door to specialized vocational training for this population, but that was not going to happen and, to this day, has not happened.

I had been in contact with Edward's middle school teacher, keeping her apprised of what was going on. When I returned Edward to her classroom after spring break, it was clear that the only immediate goal for Edward was to reassemble his shattered self-esteem.

I have never been back to the Vo-Tec. To this day, I have never received anything from them: no records, no papers – nothing. Edward doesn't even look that way when we drive by it. It's a memory, one he doesn't forget.

Third Love – Movement and Dance

For the most part, Edward has been asked to try everything a regular kid does. Early on, we tried roller skating and then roller blading. He just doesn't have the ability. He can't ice skate either; all he did was cry when we tried. We even bought figure skates for him, thinking they have more support in the ankle. It was just not there.

We have gone coasting on a golf course in a nearby town. He loves to go down, but when he gets to the bottom he yells, "I need help." I would run down and then have to lug the coaster back up. He would

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like to snowboard, but I don't think he has the ability no matter how hard I push; it's a balance issue with Edward.

Edward rides a bike but knows he is only allowed to ride in our cul-de-sac. We bought him a bike when he was ten or 11; it had heavy-duty training wheels made to hold his weight. He came home from school one day and said, "I want the training wheels off." Carolyn and I took one wheel off and ran holding his seat. He was wobbly and unable to steer, but all of a sudden, he pedaled off screaming. Within three days he rode without any training wheels. Edward loves to go fast on the bike or the sled, but he's not thrilled with roller coasters. He'll tell you he's afraid of heights, but he's not afraid on a plane, nor was he afraid at the top of the Eiffel Tower.

The only thing Edward has asked for was a driver's license. At first I gulped, but then got the manual for him and handed it over saying, "Now you have to read it and learn it." "But I need your help!" he exclaimed. "You don't help me drive, I can't help you," I replied. "Well, you have to come in with me." "No, I can't. The policeman will be there with you, not me. You have to take the test and he will tell you if you passed." That ended that. He has never asked again.

Aside from riding a bike and swimming, Edward loves to dance. Years ago, we went to a party and Edward was down on the floor doing twirls. People were looking at him saying, "Look at him, he's funny." With Carolyn getting married, I decided to give them something to look at and became determined to find him proper instruction.

We began dancing lessons with Denise at her studio in Abington. Today, thanks to her, he can do the Waltz, the Fox Trot, the Cha-Cha, the Mambo, Swing, the Rumba and even the Tango, his favorite. He has been doing this for 13 years and is completely comfortable on his feet. There are 13 steps to the Tango, and each requires not only knowing which way to go, but also what to do and when. Denise titled every step for Edward: the Basic, the Diego, Sneak, Della Cruz, España, Merengue, the Switch, the Chair, the Mask, Grape Vine, Tootsie Roll, Sombrero, and the Rocking Step. She simply tells him which one is next, and he is able to do it. It takes at least two Tango songs, or about five minutes, to complete all the steps. He has an excellent memory and is smooth on his feet.

I found Denise after calling a few places. When I called a well-known dance studio, I told them that Edward has Down syndrome. Quickly, they replied, "Oh, we are not insured." I think that is what

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scares people off, but I am always up front about it. One day, Carolyn and I just happened to drive by Denise's studio and on the spur of the moment decided to stop in. She didn't hesitate, and so began weekly classes. Edward leads perfectly, holding Denise, with her eyes closed, his hand fixed in the middle of her back. When he makes a mistake, they stop. "Sorry, I'm tired," he'll say.

Edward likes being *the show*. He tends to zone out when he's on the dance floor, and surprisingly he doesn't get distracted by anything around him. Denise has tried to throw him off; she will switch songs to make him think of what dance step to do, and has even mixed up where they start and where they finish just to change things up a little.

He has been asked to come to her other classes and demonstrate for them. He has done solo recitals; they've done performances for the Plymouth Association for Retarded Citizens (PARC) and made an instructional video of themselves dancing. His coordination, his balance and his sense of timing have become extremely good. He walks like a duck but when he dances, his feet glide gracefully across the floor.

Fourth Love – Music and Girls

I've never known what developmental age Edward really is and, truthfully, I never have figured him out. Edward lives incident to incident, not day to day. When a much-waited for Miley Cyrus CD was about to come out, it was all Edward could talk about for weeks. The clerk in the store told us it would be available on the thirtieth of the month. Edward asked, "Well, how many more Tuesdays is that?" and went to the calendar to count. We were first in line. For hours, he listened to it and danced all over the house but then he took it to the gym. I thought he would show off there, but instead he began twisting and dancing to the Chipmunks. Yes, he goes from Miley Cyrus to the Chipmunks.

The show *High School Musical* irritates me to no end. If I could get a hold of Ashley Tisdale or Miley Cyrus, I would shake them for thinking they are such *big stars*. They don't even bother responding to their fans one of whom, to this day, is Edward. After that movie came out Edward couldn't get enough of these girls and was desperate to get in touch with them. In his weekly call to his Uncle Donny in Florida, Edward revealed these heart throbs and Donny listened, encouraging Edward's truly blind romance. Soon Edward began dictating letters to

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Donny to be sent to Ashley and Miley. The following is an actual letter sent by Edward:

Dear Ashley,

I am sending you a picture of myself in my tuxedo. I am more than just a fan, I am the one who got you guys in the newspapers. Will you send me a picture of you?

*Your fan,
Edward*

No acknowledgement has ever come, leaving Edward so frustrated. Once Donny printed a picture of Ashley and sent it to him. Poor, wishful Edward took it upon himself and wrote on it, “Casey, thank you for buying my CDs,” and then he signed *her* name. One of the things Edward succeeded in doing, despite not being able to read, was to look up the email address for Ms. Tisdale in one of the teen magazines he scoured in a store. He then dictated an email to his Uncle Donny to send to her – all to no avail. He gets an A for trying.

He has called the Boston Disney Station, 1160 AM, and asked to talk to the stars because, for some reason, he truly believes that he’s the one who has put these girls on the map. Why he thinks this I don’t know. The person on the other end of the phone always tells him, “Well, you’ll have to call back later.” They can sense that there’s something different about this particular caller, but they don’t have the nerve to hang up on him. The funnier thing is that to call Disney you have to be 14 years old or younger. Edward knows this and knows he is too old, but has figured out that he can use his younger niece’s name and her birth date. I told him it was against the law to call and give someone else’s name and age to get a gift or win a prize. He says he will do it until his niece reaches 15, which fortunately is this year.

Edward loves to learn the words to new songs, but he can’t read the lyrics insert because, for one thing, the font is too small. He is quite savvy and has roped in certain people to google the words and print them in a larger font. With all sincerity and in his theatrical style he tells them, “I’ve got to learn this song!” He also asks them to print a duplicate copy, “for Mom,” in case he loses his. Lyrics in hand, he will sit in his room with the door shut, his earphones on, singing at the top

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of his lungs. He can't sing as fast as the singers do, so for a while he just gets the last few words of each line, but he persists until he masters it. He has hundreds of song lists and I have thousands of pages of lyrics.

Edward also wants to learn the dance moves to these songs and is constantly writing for the "steps."

Dear Miley,

Do you know your steps to your "Hoedown Throwdown" dance? Could you send me a copy of the steps that you do with your choreographer and on your DVD? Thanks.

*Your fan,
Edward.*

The same entourage of people he has printing his lyrics are also hooked into looking for his steps online. I would love to leave a tape recorder in his room. He is his own best friend in there, carrying on various conversations and always getting the answers he wants! Whether he's talking to a music idol or a movie star, he's in seventh heaven, laughing uproariously and even talking back to them.

Edward can't get enough of movies. He can watch them over and over to the point where he knows all the dialogue. I think in a way he becomes these people. He comes downstairs once in a while and talks to me as one of the actors. He loves *Mash*, for example, and identifies with Hawkeye. He'll come to me saying, "I need my Martini."

As he has gotten older, his hormones have kicked in and girls are much more interesting. When I went to his room once to check on him getting ready for work he pulled the shower curtain back a bit and said, "Mom, I am a man trying to take a shower!" I have told him that it is all right to use his room for his "private business" and he knows that. Everyone is to knock before they enter.

One time, my second cousin, Dave, walked into the family room only to see Edward with his arm around my niece's daughter. He was rubbing and kissing Alyssa's shoulder. Dave called his wife, Vicki, who in turn yelled frantically, "Ha-zel!" I said, "Okee-dookee" and called Edward to my room. We sat down to another talk. "Those actions are not appropriate," I said. "She is your cousin. You can give her a hug and a kiss on the cheek when we come and when we go. That is

IT. HANDS OFF GIRLS! You want to do your *thingee*, you go do it in another room or the bathroom. You know the rules now. And furthermore, you do not walk up to a girl and say, ‘Hello, how are you? I want to marry you.’” Edward thinks girls are going to fall in love with him right away. I tell him that you have to be friends with a girl for a very long time. You have to talk on the phone, bowl together, go to a movie and get to know each other. After all this, he says, “I am going to make the best dad ever.” Supposedly he is 99.9 percent sterile. I have no proof and don’t want to try to find out. Even with his sister and her girls, there is no sitting on laps. All I have to do is look over at him and he’ll say, “I know the rule, Mom.”

Despite knowing what is expected, he always says in his deep actor’s voice, “I need a wo-man!!” A classmate, Martha, was a girlfriend once. He invited her to a Halloween party. Apparently, not long into the evening he left her. He did not stick to her like a date might have; instead he was flitting all around. He didn’t really get what being on a date was all about. When asked how it all went, he replied, “She dumped me!”

He is a constant surprise and through adolescence has kept me on my toes. I never know what or who he’ll be interested in next.

Adult Life Lessons

I always tell people that I can only get sick from ten at night until six in the morning. If the legs are working, I am *on*.

For Edward, it is very scary if I’m not well. When I had to tell him that I had breast cancer, he was devastated. He went to my radiation appointments with me. Before the first treatment, I had to have an EKG; he didn’t want to leave the room and said, “I’ll just stay here, Mom, and won’t look.” He sat in a chair in the corner, put his coat over his head and remained like that the entire time. Knowing a little about cancer, Edward hated when I smoked. Whenever I lit up a cigarette, he would say, “Oh, here goes Dopey having her sanity stick!”

Edward has been through a lot of life and death situations. He can handle it. He knows what a wake is and what death is; he also knows that death is permanent. He will go to a wake, hug you and tell you he’s sorry. The next day, or the day after, thoughts come back and often he is sad for a while. My brother, whom he was very close to, died in December. I told him that Uncle Joe has gone to heaven; he is up there with Grammy and Grandpa, Great Grandma and Grammy Martin. He

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seemed okay with it that night. He went to work the next day and I got a call that he was bawling uncontrollably; it just hit him. When I picked him up, he got in the car and cried like a baby. I asked him why all the tears, and he told me his uncle died. What I told him then, as I had years ago, was that God put us here. “He’s the chief and when He decides it’s time, He’s going to bring you home so you won’t be sick anymore.”

He’ll look at the picture of our dog, Tiffany, who was our best “babysitter.” Tif would get into the playpen with him and later slept right by his bed. She was always between Edward and whoever else was here. She would never bite, but if you moved and got up she would growl. Edward knew she was there to protect him. She is buried out in our backyard; Carolyn’s dog, Nicky, is in the front yard. Edward, from time to time, will go outside and sit there talking to them both. He can be emotional; tears coming and going in spurts. You never know what he is thinking, ever, even today.

I taught Edward to say prayers when he was little and always told him, “God hears children before he hears us adults. You talk to him; he’ll keep an eye on us.” Edward still says his prayers every night. He does not recite, “Now I Lay Me Down to Sleep” or the “Lord’s Prayer,” but starts off with, “Hey Pal.” He includes the whole family: siblings, parents, grandparents, even the dog. He also adds people he knows who are sick, and people he wants kept safe like his brother, Bill, who travels a lot by plane.

Edward is so programmed. Each night he goes upstairs, brushes his teeth, gets my nightgown out and lays it on my side of the bed, and then goes into his room. He gets into bed halfway. I go in, pull up his sheets, and then he puts the radio on. Every night I ask him, “Did you say ‘em?” He answers, “Not yet.” I remind him of those who need a few extra prayers and then leave the room. He calls out, “You forgot to give me a kiss goodnight.” As I leave a second time he has to ask if there is a storm coming; he cannot take thunder or any noise in the night. I walk down the stairs and hear him begin, “Hey Pal.” He ends his prayers with a line he memorized for his acting debut as an angel in a middle school Christmas play: “Glory to God in the highest and on earth, peace and good will to all men.” He has said this every night since he was six years old.

The Essence of Edward

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Edward cares about people. Our neighborhood had a lot of kids when Edward was growing up. One family next door had six children; Tommy was Edward's age. When Tommy invited his school friends over he would sometimes include Edward, but Edward would fall behind when they went into the woods and they would forget that he was even with them. Edward would have only made it to the other side of the brook in our backyard before he began calling out for me, but he'd go with them the next day again if they asked. Other neighborhood kids would always say "Hi" to him, but because his summer days were spent at the Swim and Tennis Club, there wasn't a lot of interaction. Edward, however, liked to think that *he* looked after the neighborhood kids. Once, he warned some of them not to ride their bikes off the black top because he had just been chased by a hoard of yellow jackets.

Another neighbor had a pool, so many of us gathered there often. One of the other fathers in the neighborhood was so good to Edward that I would introduce him to newcomers as Edward's *other* father. Edward touches people. You have no idea who or when. And Edward doesn't even know the extent.

He was always close to my brother and to his teacher Anne's husband, John. When Anne and John took Edward's class to New York City one year, Anne's dad also became special to him. One story he likes to tell people is how Anne and John ran him into McDonalds in New York City when he was so sick with a stomach bug. He has never, never forgotten and says, "They were so good to me." Another endearing person was Jim. He was the dad of Christine who was on Edward's swim team, the Sharks, for years. Jim often took the two of them to events and rooted Edward on. Edward to this day says, "Jim treated me like a son."

When Jim got sick, I would go and clean his house and Edward would visit, sitting by his bed. Edward still talks to him every time we go by the cemetery. I don't know what the specific influences are, but certain things and certain people he does not forget. You don't have to do a lot with him, just spend a little time with him.

Despite his aggression in grammar school, Edward fortunately outgrew having to bang heads to get his way and has grown into a person who gets along well with others. He had no problems in high school with other classmates, and now has no personality problems with his manager at work or fellow employees.

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Edward can be kind and thoughtful. As a reward for being a ten-year employee at Stop and Shop, he was given a catalogue and told to pick out a present for himself. He picked out fresh water pearl earrings for his niece McKenzie, who at one time irritated him to no end, but whom today he loves like a sister. He has also taken to calling his sister, Carolyn, every night just to check in.

As thoughtful and sensitive as Edward is, he also has a definite stubborn streak. He is a manipulator. Things have to be done Edward's way and in Edward's time. For example, he wanted to thank people recently for their birthday gifts. I bought the cards and he sat at the kitchen table dictating each letter. He signed them and said, "We'll mail one at a time." I said, "Well, I will put them in the mailbox as I go by tomorrow." "No," he said, "One at a time. I got the presents one at a time, we'll mail these one at a time."

Edward also likes his things arranged the way he likes them and, despite it appearing disorganized, he can find most everything he needs in his room. He does not like it when I suggest cleaning in there. One day when he heard Anne, his teacher, was dropping by, he told me he didn't want to go to work. He hounded me, asking, "What is she coming for?" I told him that Anne was coming to ask me some questions. He persisted, "What about? Are they about me? Are they about picking up my room? Are you going to show her my room?" Keep in mind, he will not pick up anything if he can get away with it.

The other part of this streak is that we go where Edward wants to go – *his* stores and at *his* pace. We poke at Wal-Mart in their electronics section, but we don't go to Wal-Mart's woman's department or housewares, even if I need something. We go to the music store in the mall and he'll say, "I'll just look around," and I stand there. Sometimes employees have gone to the back room to get me a chair while Edward is still looking around.

Edward can try your patience. And one day he did. Driving home on this day, I slammed on the brakes and I told him to "GET OUT. You have pushed me to the limit; get out of this car." He knew I meant business and he cried. But he learned. Not much later, in middle school, when he was asked to do something, he turned around to his teacher, Laura, and said, "Ms. Breault, you have pushed me to the limit." Incidentally, he was not a saint at school all the time either. Once, he was sent to the hallway for something he did in the classroom. While there,

he noticed that all the lockers had color-coded padlocks. Mischievously, Edward decided to change the colors on all the locks, except for his own. Nobody, but Edward, could get into their locker that day.

What does he do with disappointments? He will pout and stomp, and with tight lips in an angry, frustrated voice he'll say, "MO-TH-ER!!!" I ignore it now and say, "I don't like that – get rid of that tone. He goes to his room (what he calls "his living quarters") and gets over it. He can also get an attitude if he doesn't get his own way. He will cross his arms, put on a sour face, complete with furrowed eyebrows, and become testy. The theme one year for a Halloween party in middle school was *Snow White and the Seven Dwarfs*. You'll never guess who Edward wanted to be – Grumpy. How fitting! What you see is what you get. He does not know how to cover his reactions, even if it gets him into trouble. At the same time, he will take the shirt off his back and give it to you if you ask.

Harry

My husband, Harry, has patience for every other young person – even those with special needs – but not for Edward. From the beginning, Harry was too involved with his own life, saying, "I have to do this or that," or "I have to go here or there, so have dinner ready because I have to be out of here." He has always been self-absorbed.

For some reason, Harry has never been able to use the right tone of voice with Edward. I have learned that you cannot talk to Edward with a temper, nor can you show tension because that stresses him out. Harry and I can't even have an argument when Edward is home; Edward will walk outside the house and I won't know where he has gone. So, no matter how mad I am at Edward or how frustrated I am at what he has done, he does not go out the door without a kiss and an "I love you" from me.

Sadly, Harry has never been able to show much affection for Edward. Even as a youngster, Edward used to say, "I want to give you a hug goodnight," and Harry would push him away saying, "No, I don't want a hug." Harry might not be a hugger, but when you have kids, especially one with special needs, you just have to do it.

It's odd, but Harry has been to several dinners for the "Best Buddies" program (students who take special needs kids under their wing). He sees the loving interactions these people have developed – how much they have given and how much they have gained. He seems

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proud of *those* special needs kids, yet he is still unable to give Edward the love and attention he craves. I have to bite my tongue.

Harry coaches youth basketball in Brockton, but can't make it to Edward's baseball games or weekly bowling events. It's hard to explain, but everyone who knows us knows that Harry simply tolerates Edward. Yet, to this day, if Harry is sick, Edward is the first one there to comfort him.

But now, Harry is actually trying to build a connection with his son. I'm afraid, however, that his new efforts are a little too little, and a little too late. I wonder why he waited so long? He is starting small, doing things like taking Edward to the gas station or asking him to go for a walk. Edward says "No" to the walk because Harry moves too fast. Harry does not know enough to slow down for Edward, but I think he would for someone else's child.

A big part of the problem is that Harry has not learned Edward's world. If Edward needs something, or if anything goes wrong, he comes to me immediately. But if I am not around and Edward asks his father for help, Harry says, "Go call Carolyn, or call your mother on her cell phone; I can't leave right now." He would rather not be bothered and expects someone else to handle it instead. On one occasion when Harry did go to pick Edward up following an event, the supervisors wouldn't let Edward leave with him until Edward finally spoke up and said, "That's my father."

But, when Edward does the good stuff, Harry is there to take a bow. Harry has always made a point of going to Special Olympics because, in that venue, Edward is a star. Harry enjoys the recognition and likes to share the credit for his son's successes. Harry tells co-workers at the office about his Down syndrome son, but he tends to exaggerate his role in Edward's life. I get angry and embarrassed about Harry's inability to have a good relationship with Edward, and I'm not optimistic about it improving.

High School Training and the World of Work

Edward's high school years, from ages 16 through 22, were spent in a substantially separate program learning not only various vocational skills in actual work settings, but also corresponding adult responsibilities and behaviors. At first, Edward balked in his "King Casey" style. He felt above many of the tasks, such as sweeping, cleaning or serving. At home, he was fine letting me, "Mother," perform all household

chores including making *his* bed. Once, while making his lunch, I said to him, “Edward, you could be doing this yourself.” He replied, “Well, if you weren’t here I would, but you are here.” Then he sat down. His teacher Anne, in his high school program, quickly stripped him of his crown and, through behavior charts and verbal praise, Edward began to see the benefits of growing up.

In the summer, his program consisted of paid piece work in the morning followed by a woodworking class in the afternoon. He was picked up early from home and left off at the high school before the program began. Edward would find a bench and promptly fall asleep. For the first few days nobody woke him, but others in the class commented, “How come Edward is sleeping? He can’t get paid if he’s sleeping.” Sure enough, staff docked his pay. I pointed it out when the check arrived. “See, you can’t sleep and get paid. No workie, no money!” For some reason, that registered with him.

Edward has been employed as a bagger at Stop and Shop for nearly 14 years. His first job coach after high school took him to various stores in the local mall to fill out job applications, but nothing came of that. When a Stop and Shop opened nearby I took him in to fill out an application. He was hired right then and there, and the same job coach came back to work with him for about six weeks. With that guidance, Edward learned the *right* way to bag food and, equally important, learned the Stop and Shop employee rules, including those about break time. However, after the job coach left, Edward, on occasion, resorted to his conniving ways. One day, for example, he followed protocol at first, asking his cashier for a break to go to the men’s room; but she soon wondered what was taking him so long. The boss went to look for him and found him in the book aisle reading magazines. When it happened a second time, management handled it right then and there with a verbal reprimand. The day he was hired, I told them not to give him that inch, and now they don’t. He can manipulate any of us and, on those days, I tell him, “If anyone stole you, they would call and pay me to take you back.”

Work is now automatic for him. I reinforce that he must do his job and do it right, “otherwise they will fire you.” I often repeat our mantra: “No workie, no money.” He knows exactly what he is supposed to do and where he is going. If things change, however, he must know ahead of time or he can become frantic. Every day he is up at seven, gets his insulin and continues with the rest of his morning routine: breakfast,

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shower – you can tell he is showering when you hear the water running along with loud sighs of *Ahhh* and *Ooooh*. He dresses in the clothes he laid out the night before and finally has some caffeine: his diet soda. He is now all set to go, since the night before he put a hanky and his Acucheck in one pocket, cough drops and spray sanitizer in another, and a bottle of water in his gym bag. He is gone by 9:15 – as long as everything has been put in the right place.

Adulthood – New Challenges and Regression

People say Edward is what he is today because I pushed, but I only did so because he had the ability. My goal was to keep him busy all through his school years, so I made sure he got to the gym, dance classes and bowling on weekends. Now, he continues to bowl once a week and he is still a fixture at the gym, but dance has ended for him. Through happenstance, however, Edward began horseback riding lessons a year ago. When he met his instructor and two of her horses, Mia and Summer, things seemed to click. Each week, entering the stable, he immediately starts talking to his “pals” and continues to chat them up while he strokes their necks and brushes them. Edward is used to wearing shorts or sweat pants but those would not do for riding; we had to go out and buy all the gear – the jeans, the boots, the shirt and the helmet. He has been taught exercises to do before he mounts the horse and sits erect in a Western-style saddle. He walks and trots the horses as Shannon leads them. He has been in two shows for beginners, meriting two ribbons. One of the show requirements was to pass by the judges, tilt your head and give a wink. He loves putting on his spiffy outfit – especially the cowboy shirt – and once, as we were leaving for the show, asked, “Am I the main attraction?” One of the onlookers said, “He looks like he has ridden for years.” Wouldn’t you know, he is center stage at these events.

Edward still needs routine, but he does not need a clock or a calendar. He can look in the mirror on a Wednesday night, for example, and say, “I need a haircut.” He knows every fourth Thursday – one of his days off – we go to the barber. Order and predictability in his days assures him that all is well with the world.

I really don’t know what to do now that he is 38. He is not able to go to a football game, he can’t go to the movies, and I guess, I’m the one feeling guilty that there is nothing for him to do. Sometimes we go

down to Star Land and hit a bucket of balls. It's embarrassing that it's just him and me. But I am sure he is not the only one in this boat.

His isolation might be part of the reason he has regressed in some things. Money, for example, doesn't register with him correctly. His Uncle Donny sent him \$50 for Christmas. I reminded Edward of the amount when he was about to thank Donny in his weekly call, only to hear, "Hey, pal, thanks for the five bucks." Back in the day, he learned to count money by recycling cans. He turned his nickels in for dimes and quarters, and eventually could count up to a dollar. He can't do that anymore. When he was in high school, he and I planned a trip to England to see his brother, Bill. Edward became obsessed with finding recyclable cans, even telling Ellen, his bus driver, "Mother said that I have to save the soda cans to pay for the ticket." He truly thought that. Edward continues to save for vacations and Ellen still saves cans for him. When he gets his paycheck, we cash it at the bank. Right then and there he takes out the quarters and the one dollar bills, then, in his cavalier style – a nod of his head and a roll of his eyes – he says to the teller, "Give the rest to the 'cheap skate.'" And off he walks. His change and his dollar bills go into his top drawer for "vacation." With his stash of cash, I hear him tell people that he has money "out the ying yang."

From his paycheck, he is allowed one treat a week, that's it. He will buy a DVD or a music CD. People try to spoil him. I finally had to put my foot down with his Uncle Donny who likes to buy him things, saying, "Don't *buy* Edward. Edward gets to buy one thing a week, that's plenty. If he doesn't have enough money, then he can't have it."

When we plan a vacation to see relatives, he can't wait to go. He looks forward to fishing with one uncle in Oklahoma. He learned to cut worms in half and then says, "hook 'em up." He will spend hours casting out for catfish. Other times he looks forward to the swimming pool, but from suppertime until bedtime it is down time for him, no matter where we go. So, when he is asked, "How was your vacation?" he answers, "All I did was watch television." He might have been busy the entire day but all he remembers are his endless nights. He does sit down and play board games or cards, maybe Fish or War, but only to a point.

This is all new – his age of adulthood – a place that I have not been in before but am surely in now. At this stage, it is getting tougher to keep him occupied. He works hard three days a week. The nights after work are not too difficult to fill, but when it comes to his days off,

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I hear, "Well, what are we going to do tomorrow?" Those days, if I don't keep him busy from 6 am until 9:30 pm, he will say, "I am bored out of my tree." If he were in a residential home, there would be people interacting with him. Here, he is withdrawing.

I have called a nearby group home in an effort to link him to activities and people he knows, but I get little information back and other agencies that do offer activities are very expensive. The ARC (Association for Retarded Citizens) offers classes but they don't interest Edward. Go and learn hygiene? He's done it. Sex ed classes? He's been to them. Cooking is hardly relevant or exciting and Arts and Crafts classes are not his cup of tea either. I would love to get him back into swimming; it would be great for his diabetes and his skin, but now he plays when he swims.

Edward would probably do more if he had someone close in age with similar abilities, but this social vacuum has a lot to do with his odd diet, the restrictions from diabetes, and people his age who seem to have tough speech impediments. A dance is scheduled for the spring, but he is not that excited. To begin with, he sees that others don't know how to dance; he also can't eat what is put in front of him and he can't stay out until 11 o'clock unless I come with his insulin. He is very aware of what he is, and yet he is choosey about who he interacts with. He doesn't need much; you don't have to spend money or take him to fancy places – just an hour with someone makes his day.

Reflections

It's obvious that I have been the mainstay here 24/7. Harry went to work; I imprisoned myself and I am still there. I do not go anywhere without Edward; that is the bottom line. He is at work with people I trust and then at a gym where I am completely confident staff will treat him well. I can go any day from noon until 4 pm and have peace of mind. But, leave him with just anybody? I couldn't; panic would set in. I would not even leave Edward here, alone with Harry, because of his diabetes. I could leave him with Carolyn or Bill, but not Harry.

Raising him is a job. It's full time and it's exhausting. Edward will never be my lawyer or my doctor or even take care of himself. I have found that in the past, and even now, I can always find a reason not to go somewhere or do something. Maybe I use him as an excuse, but Edward is my priority. Edward thinks it's funny when I tell him he is my third leg. I am always leading, but there he is walking right behind

me. His life, his entertainment and his health all come before mine; but he would not know that.

We are compatible, but when I do something he doesn't like he'll say I am an itch with a "b." One day, I got so mad at him I let loose and said, "I am going to put you in a home." "You're never going to put me in a home, are you?" he practically begged. As angry as I get at him, I have to reassure him that he is here to stay. I tell him that I am sorry. "I lost it. You pushed me to the limit." I could never put him in a home; it would break *his* heart, not mine.

Some days you just want to hide away, but you can't. You have a responsibility. If *you* don't do this, who will? I can't escape but I can get engrossed in cleaning a room or working in the yard. There I can leave for a few hours, mentally. You take care of anyone you love. Having kids means they are always a concern; the only difference is Edward is full time.

Edward is considered moderately high functioning – there are others who are even brighter and I do get envious of them. There are many days when I feel as though I did not do enough. I think, "I should have done this; why didn't I do that?" Then you have days when you just wonder where your life would have gone, what direction? I have no idea. I have always thought that there are things in life that are meant to be, and some things you cannot control. I was born at a certain time and on a certain road. I was not meant to be a nurse or a teacher and, for some unknown reason, I was meant to have Edward. From day one, when he finally succeeded at something, it made it all worthwhile.

He was meant to come right here, to this house, whether it was for Bill or Carolyn, or even if it was just for me. Hopefully, my grandchildren will get what it means to have Edward in the family. He has touched everyone in my extended family and brought us closer even though we are in different states. I look at other special needs kids and their parents and wonder, "How can you *not* spend the time? How can you say 'I'm going away' and just put your child somewhere?" I see that being with Edward every step of the way has benefited him. I have to keep telling myself that Bill and Carolyn are going to take care of things. I worry, you don't know who is going to end up being here with him when he needs someone. It's the unknown, again. I can only pray that he will always be treated with respect and dignity.