

## **Chapter 18 — 1987: Broken Hearts and Hand-Me-Downs — A Christmas Story**

It was already the 19<sup>th</sup> of December. Tomorrow my mom and sister would arrive to spend Christmas with us, and I still wasn't ready. I would never be ready, of course, but that was beside the point. The immediate problem was I didn't have a gift for Ellen. I had gone through the usual motions, looking through my closet to see what hand-me-downs I could part with, looking through my trunk of fabric for just the right piece with which to make her a ruffled skirt or a pretty blouse. She so loved the style of clothes I wore. But as always, my best laid plans had gone astray.

Now I was dragging my son into my favorite lingerie shop to fill the order Mom had suggested on the phone. "Ellen could really use a new slip." I had the pattern and fabric at home to make her one, but I just couldn't get it done. Part of the reason is when I sew, I think about the person for whom I'm sewing, and I could not allow myself to do that thinking before Ellen was here in the flesh.

I found a pretty slip, off-white with a decorative stripe woven into the fabric, which wasn't too expensive, and David found a cute pair of red and white candy-striped socks we were both sure she would love. I added a second pair of black and purple checkered socks so she would have a gift from Dan as well, and we headed home. I remember thinking how nice it would be for her to have some prettier lingerie than the plain white Mom always bought for her. I probably commented on it aloud to the disinterested sales clerk.

My sister Ellen is 34 years old. She wasn't expected to live past 18, according to the knowledge of the time. I guess we all must have been counting on that, my father, my brother, and I, and it was that knowledge which shaped our attitudes toward her. But she didn't die. She lives still, much to my torment, much to my father's sorrow, much to my brother's disdain. And to my mother's what? Her anguish? Her martyrdom? Or her silent relief that medical science has leapt forward so remarkably in Ellen's lifetime.

I have never loved my sister. Her presence in my life has always been a burden on me, a source of anger and frustration. She was born 9 days before I turned 2. Although I have suppressed most of my childhood memories, I remember when Ellen was born. I remember being rudely moved from bed to crib by a woman I did not like who was punishing me for not lying down quietly and taking a nap. I was probably responding to the separation from my mother who was giving birth to her third and final child. Very final. My father had a vasectomy shortly after my sister was born. "The fourth baby would have two heads," he declared.

According to the story I was told, my mother did not know until Ellen was 6 months old that she had Down Syndrome. My father carried that burden alone until he could not hide it from her any longer. Born with a stomach obstruction, Ellen required surgery for her to live. In 1952 Baby Doe

would not have been allowed to die.<sup>1</sup>

My mother should have known that something was wrong, I reasoned. Even as an infant, Ellen looked different. Granted, Mom’s two other children were vastly different. Tom had been born with an obvious birth defect — a cleft palate requiring several surgeries — and he developed somewhat slowly in his infancy. Then I came along and skewed the standard, walking at 9 months to my brother’s 22, verbalizing frantically in the face of his silence.

Perhaps my mother believed Ellen was like Tom. Perhaps she hoped so, anyway, for by the time she was born, just after he turned 4, Tom had caught up with me, surpassed me, and begun to show the fearsome genius which would eventually cause him no end of grief. How can a Caucasian mother look at her infant whose eyes are both clearly crossed and slightly slanted and not wonder if something might be wrong? Of all the questions I asked my mother in trying to puzzle out a solution to my feelings toward my sister, I never asked about those early months.

I grew up knowing my sister was retarded. Although this word is no longer in vogue, the definition — “slow or limited in intellectual development, in emotional development, or in academic progress” — describes Ellen very accurately; she was slow in all three areas. As an adult, she achieved the academic level of an early first grader. She is able to identify letters and numbers, but is unable to puzzle out any but the simplest words. Except for her phenomenal memory for birthdays, math is a total mystery.

Emotionally she is in her early teens. Although she seems to have a great reservoir of love for everyone around her, she functions on a level of maturity which remains self-centered. She is particularly jealous of my son, who has taken away her identity as “baby of the family.” She refers to him in the same context she refers to animals, calling him “my cute little nephew” in the same tone of voice she talks about “my cute little dog.” The fact David is now a teenager does not appear to be a factor in her appraisal of him.

One of the few incidents I recall from my foggy childhood is folding diapers atop the dryer in the basement of our home. I was eight. Ellen was six. She did not stop wearing diapers at night until two years later.

There are black and white photographs to help me fill in the blanks. There are pictures of Ellen scooting around the floor on her diapered bottom, hands between legs, bottoms of feet pressed together, cloth doll gripped firmly in teeth — her own invention of mobility to replace the crawl she never learned and the walk she had not yet attempted. The expression on her face is one of rapt joy.

---

<sup>1</sup> “Baby Doe” was a baby born with Down syndrome in 1982 in Bloomington, Indiana, whose parents declined surgery to open the blocked pathway from her esophagus to her stomach, leading to the baby's death.

She was a pretty child then, lithe and lean — the look of stupidity had not yet marred her face. She was, perhaps, two or three.

Ellen remained an infant for many years. She walked at four, a feat possible only through the purchase of a trampoline to exercise her on. I gained vast pleasure from the presence of that trampoline in our back yard, but I was never allowed to forget it was bought for Ellen and she always had first chance to jump on it.

In many ways, that trampoline was my only physical outlet. Diagnosed with a heart condition when I was three, I was restricted from physical activity; but somehow bouncing on the tramp was not considered exercise, because my parents looked at it as a form of physical therapy. It was the one place I could be outside without getting in trouble. After years of spotting for my sister to make sure she didn't fall through the springs, I was something of an expert, at least in my own mind. Little did I know that others used trampolines for all sorts of tricks and flips. It kept me fit every summer until ninth grade, when a neighbor girl fell off and broke her arm. There was no lawsuit, because people didn't behave that way in those days, but soon after, the trampoline went away.

Ellen must have been about four or five when the pictures show her beginning to look obviously different. She is now too big to be playing with the colored beads she is photographed with. But perhaps it is my own prejudice showing through. To one who does not know the circumstances, perhaps she looks normal as can be. The pictures, of course, are at my mother's house. Knowing how I feel, my mother tried very hard to leave out shots of my sister when she made an album of childhood pictures for me.

The few pictures I do have of Ellen bring back crushing memories. There is one of the three of us, Tom holding Ellen's hand, me holding Midnight, the huge black cat I loved so much, the very one my mother would tell me a month or two later had been returned to the pound for scratching my sister.

I think that incident must have been the beginning of my inability to forgive. It was the beginning of my understanding of what our parents meant when they termed Ellen "special," their explanation of why she would never be like Tom and me. She had to be given special consideration because she wasn't normal, they often reminded us. But even in my youthful anger I knew the real problem was that Ellen was spoiled.

When Tom and I ganged up on her in our on-going fight over which television programs to watch, our parents bought Ellen a television of her own. While we got our knuckles rapped for reaching across the table for the salt, Ellen sat chewing with her mouth open, food dribbling down her chin. She was exempt from learning table manners because she was "special." And when it came time for parent-teacher conferences — after I was in junior high and Mom was working full time — she could only take time off if the conferences were at Ellen's school.

Even now my anger seethes when I recall these childhood indignities. I could have been a drug addict, a part of me still argues, and Mom wouldn't have known or cared. Instead I was a food addict who weighed a whopping 230 on graduation day. My parents, too, are heavy, and so is Ellen, now. She looks like a typical person with Down Syndrome, her barrel shaped body a dead give-away. But she never had that body shape until our father turned his back and walked away for good, and she learned to eat herself into oblivion like the rest of us.

But why the anguish after all these years? Why does it come up now when I've lived so far away for so long going home again seems like some vague dream?

Despite my careful preparations, I dreaded Christmas more than ever. I dreaded it so much that for the first time in his life my son heard me say, "I hate my sister." I was shocked, because I had thought that I was finished with all that old anger and hatred. Instead I found that I had come full circle.

I had put away my hatred for the child who will always be a child. It first began to die when I moved far enough away from home that family visits were annual at best.

Four years earlier, with a great deal of finagling and much difficulty, I had managed to give myself the gift of a life-long dream for Christmas. That gift was having my mother to myself. With the help of my father and brother, my aunt and cousins, and many of my mother's friends, I arranged to send my sister to Ohio for Christmas while my mother came alone to visit me.

For a whole week, I didn't have to share my mother for a single moment. I didn't have to wait until Ellen went to bed before I could talk to my mom. I didn't have to worry about being embarrassed in public or not being able to go places which were inappropriate for Ellen to be. Mom was MINE. I could take pictures of her without my sister being in them. We could go for hamburgers at 2:00 in the morning without worrying about Ellen waking up alone. It was wonderful. We talked and talked and talked, and in that short time we managed, in some small way, to make up for 30 years. Mom's understanding of my feelings toward my sister was remarkable, and I continue to marvel that my anger toward my sister does not appear to hurt her.

The following year when the coming Christmas brought Mom and Ellen for the usual week-long visit, I was so distraught by my own situation that I hardly noticed Ellen as I dealt with more pressing turmoil. We were living in a huge parsonage, experiencing the insanity of trying to minister to a small community where we didn't fit in, constantly running back and forth between church and parsonage for holiday preparations and finally services. The size of the house was important because it was easier to get away from each other in spite of the single bathroom. The insanity was important because it so consumed my energies and my attention that I barely noticed Ellen's presence in my home.

The following year they didn't come. I don't remember why. Perhaps it was because we had no room for visitors in the small apartment we moved to after leaving the ministry.

Our new apartment is much bigger than the last, but it does not have the necessary layout for getting away from guests easily. Mother and Ellen would sleep in the livingroom, the only access to the kitchen, which meant that when Ellen went to bed right after dinner, the rest of us would be required to do the same.

Logistics aside, there was some deep-seated reason that I could not face having Ellen come to visit this past Christmas. I spent the last two weeks before the visit bombarding my husband and friends with the fact that I could not face her coming. All the anger was back, all the helplessness of being forced to deal with someone whose very presence made me physically ill — in spite of the fact that she seemingly loved me very much.

I tried so hard in those two weeks to find some ways to approach the situation, some way to help me put aside the anger and try to love her in return. I finally settled on the idea that if Ellen were made up of half of my mom and half of my dad, both of whom I loved very much, then maybe it would help if I could see my parents in her — or her in them. But when reality struck and she came into my presence once more, the theory vanished as though it had never been there.

There was no way out of it. When the plane landed on Saturday before Christmas and my mother stepped off, there was Ellen right beside her. One look at her was all it took. Everything came back in a flash — all the anger and loathing and humiliation at being related to . . . to *this*.

I cringed when she hugged me, there in the airport, and I didn't stop cringing until she got back on the plane a week later to fly back out of my life for another year.

But it turned out not to be another year before we were together again. In July I found myself at a family reunion in Ohio where Mom, eager to visit old friends in her home town without the encumbrance of Ellen, left me in charge of this sister I sometimes loathe. For some reason it was better this time — perhaps because I was in charge. Or perhaps it was because I was in the presence of loving family members who didn't know me well and were concerned about my attitudes towards this cousin they all cared about so much.

I discovered that Ellen wasn't nearly as frustrating to me when our mother was not around. I found that I could impress my will on her to a certain extent, and she reacted to me as sister to sister — complete with sibling rivalry! She paid more attention to her table manners than usual. She admired my clothes, asking for a skirt for Christmas like the one I was wearing. She even made an effort to break the pattern of going to sleep immediately after dinner so I could visit longer with our cousins.

And somewhere in the midst of it all, I realized that I am not really angry with Ellen for being what she is. Rather I am angry with the situation. I still move in and out of being angry with Mom for not putting Ellen in an institution where she can be with others like herself, where her social life isn't hampered by society's conventions. But I am not responsible for my mother's decisions, and often we have talked about the fact that she and Daddy did the best they could.

I am angry because the situation makes it harder for me to be alone with my mom. I want to be alone with my mother because when she and Ellen are together, sometimes Mom seems retarded too. My intellect tells me that she has achieved a way of relating to Ellen that works just for them. My jealousy suggest that they share a kind of love that I'm not party to. Logic aside, my mother is a different person when Ellen is not around and that different person is the one I want to spend Christmas with.

And now Christmas is coming again. Mom has made the usual innuendos, first in letters and later in telephone calls, that she is looking forward to coming for Christmas. I will make no attempt to discourage her, because even in the longest week of agonized visiting, there are fragments of togetherness between just Mom and me, stolen moments when Ellen goes into the bathroom or wanders off to the kitchen for a drink.

Once again we will plan our Christmas around their coming. We will wait until they arrive to decorate the tree, because Ellen so loves hanging the shiny blue balls on the branches she can barely see. Somehow on our limited budget we will find the extra needed to shower her with the presents she enjoys so much. There are plenty of ribbons and wrapping paper left over from last year. Every package for Ellen will contain something new for her to wear.

Because once again I am going through my closet looking for the hand-me-downs my sister loves so much. Twice now I have been through my trunk of fabric, searching for something to make her a long skirt like the one I wore last summer. If I don't find anything, or if I can't get it done, I'll give her my skirt and find another for myself.

And as I contemplate where I'm going to put the Christmas tree, I consider how to rearrange our home so that Ellen can go to bed right after dinner and I can have Mom to myself for an hour or three.