

My Sister Janet

I graduated from high school in Waverly, Iowa, on May 25, 1948. The previous few months had been a tumultuous time for our family. My brother Don had moved back to town with his pregnant wife and three kids. Their third son, Douglas, was born in February and died in April. My brother Ted had married the year before and his first child, Lynn, was born in April. Then I had learned recently that my 43-year-old mother was pregnant with her fifth child, a surprise—and a cause for concern—for everyone. My parents had bought the local greenhouse and flower shop four years earlier and my mom was a key figure in keeping that new business going.

I was scheduled to start my first year in college that fall, having qualified for the Naval Reserve Officers Training Corps (NROTC) program at a school in New York. However, my tenure there was very short-lived. I quit in early October. That is another story, but I mention it here because I recall that one of the reasons I gave for my failure to adjust was that I was worried about my mother. That wasn't my primary reason. Mostly, I just wasn't ready emotionally to deal with being so far separated from my close-knit family for the first time in my life. It did indicate, however, that a pregnancy at her age concerned me...and I was glad to be back home well before the delivery.

My sister Janet was born on November 10, 1948. The reason she was born on that date was that pheasant season opened on the 11th and the obstetrician was an avid hunter—so he induced labor to assure that his pursuit of the birds would not be interrupted. Early on, we were advised that the baby had experienced some neonatal problems—primarily with her heart—and that she might not live beyond age twenty. Apparently her heart formation was incomplete and there was leakage of blood between the chambers. However, I don't recall learning of any other problem till several months later. Then I learned that she also had Down's Syndrome. That reality would dominate family life for the next half century. This is what I can recall from those fifty years.

At the time Janet was born, our family was living in an apartment over the workrooms in the back of the greenhouse. It was a very small apartment. My brother Tom (age 13) and I occupied a pair of double bunks in a Lilliputian bedroom. The master bedroom was somewhat larger, but now it also had to accommodate the new arrival. Life was very different in that apartment as the new arrival became a major part of our lives.

I don't recall that, in her earliest days, Janet impressed me as being any different than what I might have expected if she hadn't been a special needs child. She spent her days eating, sleeping, soiling her diapers— and crying, typically whenever one of those other needs was neglected. She certainly didn't cause me to lose any sleep and her presence never interfered appreciably with my activities. As far as I could tell, she seemed to be like any other infant her age. And we had a means of comparison living next door, where brother Ted had just moved in with his wife and infant daughter. An early photo of Janet is shown here.



Looking at that photo now, I can see the indications of her Down's Syndrome—the slightly slanted eyes that gave rise to the

description “Mongoloid” that was common in those days and the tongue that always appeared too big to fit in her mouth. However, until I began to observe these and other symptoms of her special needs as she grew older, she was just my baby sister. Here is a photo of Janet and Lynn in matching strollers. Also present in this photo is the family dog, Sam, who became Janet’s companion (and protector) after she became a part of the family. In fact, I can remember once



when she was in her stroller with Sam in front of the flower shop when the mailman came by. He had to call for help to get by the dog.

Because I was then living in the family apartment and working in the family flower business, my contact with Janet was fairly intimate for the next two years. I was right there as she grew into a toddler. I don’t recall that her physical development was retarded a great deal in those early years—although she was always small for her age. She just continued to be my little sister.

Then the Korean War started and I went into the service. For the next three years I had little opportunity to interact with Janet. During those years, however, the family had to begin to deal with the fact of her special needs. When I returned from Korea and was released from active duty, I returned to Waverly but I got married almost immediately and moved out of the family home. I did continue to work in the family business for that first year. I took the picture below sometime during that year after I returned from the Army. As you can see, she and Sam continued to be inseparable pals. She was about five years old at the time.

One particularly amusing story about Janet occurred at about that time. She had been diagnosed with a thyroid deficiency, so she had to take a thyroid supplement every day. One morning she somehow had found the bottle with her pills and had consumed every one of them. When our mother discovered what had happened, she called the doctor’s office and was relieved to hear that it would not do Janet any significant harm, but that she might be a little hyper for a while.



That day, I was working with another employee in the potting shed, which was directly below the apartment. Suddenly Janet appeared, found a box to sit on, crossed her legs and began to pepper us with comments and questions. She kept at it for the better part of an hour. Then she left just as suddenly, went upstairs and I was told that she slept till sometime the next day, whereupon she woke and had no further effects.

Another interesting episode from that time has become somewhat of a family legend. My mother had always been an inveterate coffee drinker and, for as long as I could remember, her preferred brand had always been Folgers. Then one morning, when she was preparing to brew her habitual pot of coffee, she couldn’t find the familiar can of grounds. It was not in its usual place on the cupboard and she searched the kitchen in vain. Finally, she asked Janet, “Have you seen my can of coffee?” My sister looked pensive for a moment then cheerfully remarked, “You mean the Fojers?” Whereupon, she darted into the bedroom and recovered the missing item from under her parents’ bed.

After that year, I left Waverly permanently to seek an education and a different career. So, from then on, my personal interactions with Janet were sporadic, but I was kept apprised of her progress. From what I have seen and heard of others with Down's Syndrome, her special needs were a lot less severe than many others with the same diagnosis. For one thing, her congenital heart condition corrected itself and the initial prognosis of a twenty-year life limit was withdrawn. But, it became more and more apparent that her emotional and social development was significantly retarded. Fortunately, by then the school systems in Waverly and in Bremer County had become well equipped in the area of special education so, from the earliest days, she went to public school with other kids. The classes were simply modified to meet the special needs of students like Janet. At first, she went to classes with kids her age in elementary schools in Waverly. Later, she rode a bus to classes in a nearby town where the country had established a special education school. Always, she went to classes at her grade level. And, after she completed the twelfth grade, she graduated...just like the other kids...although her achievements could never match those of her age that did not have special needs. However, the one exception was that she could always read at grade level.

Meanwhile, my parents were faced with caring for a child progressing into chronological adulthood who could not possibly fulfill anything but the most minimal adult obligations. As far as I know, the thought of putting Janet into a custodial institution was never considered. She was going to live with them—at least till neither of them was able to handle the task. With the kind of genes they had inherited, that was likely to be a long time. So, whatever Mom and Dad did, Janet was with them. And, with rare exceptions, wherever they went, she went along.

As my own kids grew older, their relationship with Janet went through a kind of evolution. She was a first-grader when our eldest was born and she graduated from high school the year our fifth came on the scene. By that time, her emotional and social development had been arrested for some considerable time, probably being no more advanced than the pre-teens—and she maintained that level of development for the rest of her days. So we watched as Janet, from our kids' perspective went from being an aunt to being more like a cousin to being more like a little sister. Here is a picture—probably taken in 1963 when Janet was 15 years old. The photo (showing Dad, Mom and Janet, plus our three at the time: Mark, Sue and Eric) was taken at a fort in St. Augustine when the family was visiting at our home in Florida. For the kids, she still acted old enough at that time to viewed as “Aunt Janet”—but that would be changing soon.



Soon after this photo was taken, I accepted a new job in the Chicago area, where we have lived up till the present. Since then, our interactions with Janet have been regular, but not frequent—usually at family celebrations or, in the later years, for medical crises. Primary among the celebrations were birthdays, although two other occasions stood out as major events. The first of these was in June of 1972 when the family honored Mom and Dad with a fiftieth wedding anniversary party at the local country club. Members of the community and out-of-town relatives were invited to join us for the celebration. On that occasion, Janet—who was 23 years old at the time—was given the responsibility of watching over the guest book. Here is a photo of her tending to that task.

The second event, held in a different local venue, was a similar party to celebrate our parents' sixty-fifth anniversary. Janet, now 38 years old, was given the same task on this occasion. The photo below shows her on the job that day.

Mom, Dan and Janet visited us at our home in the Chicago suburbs a number of times over the years. My parents enjoyed going to the horse races at Arlington Park and they would sometimes stay in downtown Chicago and take in a play at one of the theaters. In all of these activities, Janet was a participant. And she always



made money at the racetrack—never very much, because to her how much was less important than simply the winning. The reason she won so often was that she would always bet on the favorite to show (place third). Below is a photo of the three of them, taken in our driveway on one of their visits. She was probably in her thirties at the time.

I can only recall once when we had Janet at our house by herself. Mom and Dad had something they had to do which could

not include Janet. So they arranged to put her on a direct flight from nearby Waterloo to O'Hare Airport in Chicago. We would meet the flight, keep my sister at our house for a few days and then put her back on a plane to Iowa. It sounded simple enough...except, for some reason, her plane was diverted to Rockford. I got to the airport and, after a number of frantic phone calls (no cell phones in those days) and a long wait at O'Hare, she finally arrived—totally unfazed by the experience. I don't remember anything about her stay with us, but by that time all of our kids were well aware of her limitations and were able to deal with them graciously.

My brother Tom, who lives only about 70 miles from Waverly, had a lot closer relationship with Janet than I. He could make daylong visits and often did. On those visits, the four of them would often play Scrabble, which Janet occasionally won. So, given his awareness of her ability with words, Tom bought Janet a computer when they first came out with those models that were essentially keyboards that could be connected to a television. He figured that she should be able to use it to play games...which she did.



Meanwhile, Dad became fascinated with the thing and began to play with it himself. So, knowing that he had been an inveterate cribbage player throughout his life, I wrote a program that could be adapted to Janet's computer and with which Dad could play cribbage against the computer. Then, when we were in Waverly for a visit, I set about adapting my program to Janet's

computer, which was in the basement of their home. As I was unfamiliar with the version of BASIC (a programming language) that would work on her computer, I asked Janet if she had a BASIC manual for her computer. She said she did and immediately darted up the basement stairs, through the kitchen, living room and hallway, through her room and into her closet. There she located an attaché case, which she delivered to me forthwith. The manual was neatly arranged among other books in the case. I looked up what I needed to know in the manual and set it aside. Sometime later, I need to refer to the manual again and I wasn't where I had laid it, so I asked Janet if she knew what had happened to it. She said, "Oh!" with what I'm sure was much the same look of enlightenment as when she responded to Mom's "Fojers" question. Then she again darted up the basement stairs, through the kitchen, living room and hallway, into her room and her closet, recovering the attaché case, which she delivered to me forthwith. The manual was in exactly the same place in the case.

This experience highlighted a personality characteristic of Janet that dominated her behavior and her relationships with those around her...she was compulsive to a fault. Everything in her life was orderly—to a fault. I can recall once when Myrna and I were visiting in Waverly and Myrna decided to help in the kitchen by loading the dishwasher, which was normally Janet's job. When Janet discovered the work Myrna had done, my well-intended wife received a lecture on how the job *should* be done.

As Janet grew up in he family home, she and Dad became joint fans of the local sports teams—and of games on television, particularly the Chicago Cubs. In addition to the local high school in Waverly, there was a small college in town (Wartburg). So, whether the sport was football or basketball, most home games would find Dad and Janet on the sidelines as enthusiastic boosters of one or the other local team. And, they often made bets on the outcome of games on the television. Dad often rigged the bets so Janet would have a good chance of winning, but she occasionally lost—and paid up (usually a dime or a quarter), grudgingly, but promptly.

As Dad entered his late eighties, his health began to deteriorate. Suffering from congestive heart failure, he spent a lot of time in the hospital for the last year of his life. As that year was beginning, the family gathered to celebrate their 70th wedding anniversary. Regrettably, he had to be taken to the hospital the night before that celebration and was missing from the festivities. Here is a photo of Janet and Dad taken in his hospital room on the day of that celebration.



He died a year later, a couple of months short of his 91st birthday. The year was 1993 and, although Janet lived another five years, Dad's death was in many ways the beginning of the end for her as well. Although she was never particularly demonstrative, the loss of her father had a significant effect on her behavior after his death. Myrna and I had the opportunity to observe those changes, as we had become a sort of second line of defense during Dad's illness and after, when Mom was left to deal with Janet by herself. Our niece, Cindi, who has been running the family business in Waverly since her grandparents retired, had been doing a dauntless job of managing their affairs. However, the demands could sometimes become more than she could manage, particularly in medical emergencies like a broken hip. We were both retired by then and could usually be in Waverly within half a day. So we often had a first-hand view of Janet's behavior in those days.

It had been determined (I don't recall by whom) that Janet was having sufficient difficulty adjusting to her father's death that she would benefit from some psychological counseling. The county health department had a mental health unit and Janet was referred there for regular counseling. There it was determined that her penchant for meticulous organization had progressed to the point that they were prepared to diagnose her behavior as Obsessive-Compulsive Disorder (OCD). Her county health counselor recommended that she be prescribed an OCD medication (Zoloft, I think) and referred her to a psychiatrist in Waterloo to write the prescription.

During this time, I remained in regular contact by phone with Mom and Cindi. They reported that Janet seemed to benefit from the counseling, but that she was beginning to have occasional seizures. She was then referred to a neurologist in Waterloo who prescribed a drug (Dilantin) for the seizures. At about that time, I decided to check the PDR (Physician's Desk Reference) for particulars on the drug Zoloft. There I discovered that one of the side effects in a small number of patients (about one percent) was seizures. (Of course, there had been no studies using patients with Down's Syndrome.) So I called her primary care physician in Waverly, Jim Rathe (with whom I was in the Boy Scouts in the 1940s) to find out what he could tell me about the situation. It turned out that Jim had been left entirely out of the loop and knew nothing about what had been happening. After hearing what I had discovered, he said he would take her off both of the drugs and get personally involved in the situation. Regrettably, by then it was too late.

The degeneration in Janet's ability to function was phenomenal. In a matter of weeks, she went from being able to set the dinner table (as she had been doing for years) to being unable to dress herself. I don't know how long after that—but it wasn't long—before she had to be moved into the county facility for special-needs adults, about 8-10 miles east of town. I can recall visiting her there several times. By then, she really didn't know who I was but, interestingly, she always remembered Myrna. After Mom had her stroke in 1996—and became wheelchair bound—I recall that we took her there to visit Janet several times. Then Janet's condition deteriorated sufficiently that she had to be moved into a facility in Waterloo that could handle cases like severe Alzheimer's—although I don't recall that this was ever her diagnosis.

Myrna and I visited her at least once in that facility. She remained mobile, but by then she wasn't much aware of what was going on around her. Then, one day we got a call that her physical condition had become critical and she had to be moved to the hospital. We had a granddaughter in high school living with us at the time, so I went by myself to meet brother Tom in Cedar Rapids. We drove together to see Janet in the hospital in Waterloo and then back to stay that evening at his place. At about four the next morning, Tom woke me with the news that the hospital had just called to advise of Janet's passing. I'm told that my first words to him out of the fog of semi-sleep were, "Good thing I packed a suit."

Three years earlier, Dad had died the day after Mom slipped and fell in the bathroom of his room in the care facility and broke her hip (the second time in recent years). So she was awaiting surgery in the hospital when I was the one who had to inform her of Dad's passing. Now, in her nursing home, I had the same task with the news about Janet. Interestingly, these are the only two times in my life that I ever saw my mother cry.

The date was April 21, 1998. Janet was 49 years old.

Richard Ecker
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