



Joys and Challenges of Life *With* Annie

For the past 50 years,
my parents have cared for my sister who has brain damage,
solving problems as they came.

BY CHRISTINE M. GROTE

WHEN I WALK into the tidy and clean kitchen at my parents' home, decorated in cheerful shades of yellow and green, my dad is sitting at the table with Annie's wheelchair pulled up beside him, facing him.

My sister Annie has short brown hair and deep brown eyes. She is the size of a small teenager, reclining in her chair with her legs elevated. A terrycloth dish towel is draped around her neck and tucked under her chin. Although she turned 50 in May, Annie grasps an infant's rattle in her right hand.

"Oops, I'm sorry," I say. "Are you feeding Annie?"

"Just finishing," Dad answers. At 75, his once-thick brown hair has thinned and turned silver. His movements are slow and deliberate. He wipes Annie's mouth with the towel, removes the towel, then gathers the plastic cup and ceramic bowl from the table and stands.

"Hi, Annie!" I say as I walk over to her. I take her hand, holding the toy in my own as I lean down to kiss her forehead.

Annie's eyes sparkle as they dart from side to side. Her mouth opens in a wide grin as she makes sounds of pleasure, vacillating between a low chuckle and a soft holler.

"Did you know I was coming to visit you?" I ask.

My mom stands in the kitchen doorway. Her youthful face belies her 74 years, although the hair that frames it in soft curls is more gray than the brown it used to be. Mom answers for Annie: "Yes. She knew you were coming. We told her this morning."

Unexpected Diagnosis

People are curious about Annie. When someone first encounters her, either in person, through a photograph

or because I mention it, I feel a need to explain: "My sister Annie is a year younger than I am and was born with severe brain damage. She doesn't walk or talk, or do anything for herself. She basically requires the same care as an infant. My parents have taken care of her for 50 years," I say. Then I smile.

I'm not sure why I smile. Maybe it's to ease the blow that I've just dealt unsuspecting individuals who now have to look a difficult reality in the face. Maybe I'm trying to reassure them that it's O.K.; we're all O.K.

Or maybe I smile because, growing up with Annie, I know something other people don't. They see Annie's disability; I see my sister. My parents saw to that.

Named Diane Louise Smith at birth, Annie is the fourth of five children born to my parents between 1954 and 1959: Kathy, Carol, me, Annie and Jerry. I'm responsible for giving her the nickname "Annie" because, as a youngster, I couldn't say "Diane." Most other people adopted it, except for Dad.

My parents had no idea anything was wrong with Annie until she was nine months old and Dad took her to the doctor's office for her regular checkup. When the doctor laid Annie on the examining table, he asked, "She's not sitting up yet?"

In response, Dad held Annie under her arms and sat her up, but she just kind of wobbled around. The doctor said, "I want to get an appointment at Children's Hospital in Columbus [Ohio]."

My parents waited until Mom recovered from having my brother, Jerry, almost exactly a year after Annie was born. By the time they took Annie to Columbus, she was 14 months old. She wasn't sitting up, crawling or walking yet, but they weren't overly concerned: The doctor had reassured them that Annie probably had something like a hematoma, a tumor or swelling



Annie Smith can't chew food so her mother, Mary, must feed her baby food or liquid meals. Even then, Annie frequently chokes and strangles when she is eating.

that contained blood on her brain. Since the soft spot on her head hadn't closed yet, removal was not expected to be complicated.

One of the first doctors who examined Annie in Columbus said, "There can't be much wrong with her: Look at her face. She is bright and is smiling at me."

This was in 1959, before MRIs and CAT scans. They did what they called an "air test." They shaved off all of Annie's hair and stuck numerous needles into her head. Mom still shudders about it.

The test showed that there were channels and blockages in Annie's brain that were not normal. The doctor said that if you drew a line from in front of one ear across the top of Annie's head to the other ear, the portion of her brain in front of the line was gone. "It was explained to me, as best as they could tell, that she had the equivalent of a lobotomy," Dad recalls.

My parents never expected the news to be that bad. "And I wasn't the only one stunned," Mom says. "You have

never seen doctors so stunned in your life."

"We only had two choices," Mom explains. "Keep her and take care of her, or put her in an institution. How can you take a tiny baby and put her in an institution? That didn't seem like anything I could do."

The future was "a real big scary thing," admits Mom. "I really didn't have a choice," she adds.

"I wasn't willing to give her up any more than I was willing to give up any one of the other ones," Dad says. "My notion was that she's a bona fide member of the family."

Learning to Adapt

The doctors did not expect Annie to live very long. They told my parents to take her home and love her.

Over the years, Mom and Dad did exactly that. They solved problems regarding Annie's care as they came along.

Feeding Annie has been one of the larger challenges. "There was a time when I thought no one else could feed

her," Mom explains. Annie can't chew food, so they've had to feed her baby food or liquid meals. Even so, she easily chokes and strangles when she's eating.

Sometimes, if there is a sudden noise, Annie bursts out laughing. If she happens to have a mouthful of baby food, it immediately gets sprayed all over the person doing the feeding, who is usually my mother.

Growing up, the rest of us learned pretty quickly how to moderate our behavior when Annie was being fed: no quick movements, no loud or sudden noises. In fact, it was better if we just stayed out of the room altogether when Annie was eating.

Annie has difficulty holding her head up. If left to her own devices, even in a reclining position, her head will eventually fall over to one side. When my siblings and I were children, we all learned how to "fix" Annie by either gently placing her head back in her neck pillow or pulling her back up into a better position when she slid down in her chair.

In the 1950s and '60s, aids for handicapped people were not readily available. Before Annie got her first custom-made commercial wheelchair in the 1970s, Dad built three or four different chairs that he specifically designed to help hold her in place.

Making Adjustments

In addition to Annie, my parents had four other children who needed to be raised. Today, Dad says that, even though he and Mom are older, it's a lot easier for them in many ways because they have only Annie to worry about.

Dad says he is most proud of the fact that they raised the rest of us to be responsible adults "with all this going on," referring to Annie's care.

Mom is equally humble. "I feel like most anybody would feel with five children," she adds.

Early on, my parents decided to try to fit Annie in "the best that she would fit in" and to try to do the things that we would normally do if she wasn't disabled.

For example, when we were youngsters, Dad carried Annie up and down the hills through the trails at Old Man's Cave at Hocking Hills State Park in southern Ohio. Looking back, Mom admits, "That was a hard job. There was no access to getting her in there other than carrying her."

"So what were we doing at Old Man's Cave?" I ask.



(Above) Annie's cheerfulness brings a smile to the face of her mother, Mary, as they celebrate Easter in 1967.

(Above right) In 1958, baby Annie poses for a photo with her big sisters: (left to right) Christine, Carol and Kathy.

"We wanted the rest of you kids to be able to go," she explains.

Annie is actually fairly well-traveled, at least to those places a car could take us. She has been on beaches in southern Florida, as well as additional beaches along the East Coast. She has visited Niagara Falls in Canada, Washington, D.C., Chicago and Los Angeles.

"Dad was the motivator," Mom explains. "There were probably a lot of places I wouldn't have gone if it had been up to me. You had so much extra stuff and different things you had to think about when you've got a handicapped child who can't eat regular food. It was a lot of trouble."

Striving for Stability

When we were growing up, Mom stayed home and Dad worked outside the home. Over the years, Mom established a regimented approach to caring for Annie, trying to keep things on a steady keel.

Dad, on the other hand, always wanted to add the elements of inclusion and interest into Annie's life. We have a photo of him sitting on a beach where the waves met the sand, holding Annie seated in front of him. Dad looks a lot more entertained than Annie.

When Dad retired, Mom went to



work for a few years while he took care of Annie. Dad says that he became a lot closer to Annie during this period and that they "got along just absolutely fine."

Mom used to dream Annie started talking. The fact that Annie can't speak is Dad's biggest regret. "Everything else I can deal with pretty much as it comes along," he explains, "but if she is hurting, she can't tell me where."

Although Annie can't speak to us, we all talk to her. We believe she understands us and we think we understand her, in general terms.

My parents say that if they ask Annie whether she's tired at night, she will close her eyes in affirmation. But most of the time, we just recognize her moods through her body language and sounds that she makes.

Part of Mom's regimented care is to prevent Annie from getting sick because that really complicates matters. "One of the worst things that can happen around here is to put Annie to bed and have her cough," Dad explains with a twinkle in his eye. "That's a no-sleep night."

Mom adds, "Well, I can explain that." She tries to stop Annie's coughing at all costs at the beginning so it doesn't turn into strangling.

"Annie gets scared when that happens," Mom explains. "And when she gets scared, everything else gets bad, too." Mom was referring to the fact



(Above) Jerry Smith cuddles his daughter Annie, who is dressed up to celebrate Easter with the family in 1969.

(Left) By 1963, the Smith family had grown to include little Jerry, enjoying a vacation with his mom and four sisters.

Making Churches Accessible

BY MARY JO DANGEL

“Every person should be welcomed into the worshiping assembly with respect and care,” explains *Built of Living Stones: Art, Architecture and Worship*, a 2000 document by the United States Conference of Catholic Bishops (www.usccb.org).

These guidelines note that Pope John Paul II called the Church to overcome “the tendency to isolate, segregate and marginalize” people with disabilities.

All construction, whether new or renovation, “must fully integrate the demands of the liturgy with current laws, codes and ordinances for persons with disabilities,” stresses the USCCB’s document. In addition, people with disabilities should be consulted in the planning process.

Although such endeavors can be challenging and expensive, especially when renovating older buildings, the document explains, “The goal is always to make the entire church building accessible to all of God’s People.”

that if Annie gets upset, it tends to trigger a seizure.

We all know to watch for seizures. Sometimes, it’s just a twitch of Annie’s bottom lip. Often, she just zones out and kind of stares into space. We call her back from those episodes by saying her name.

Her seizures haven’t been severe since she was quite young. But one time, Dad ran frantically down a hospital corridor with Annie in his arms while she was having a seizure and not breathing.

Life’s Presents

Taking care of Annie has been frustrating at times. She eats at different times than the rest of the family. Because of that, or the need to put her in bed, her schedule often conflicts with my parents’ activities.

Dad says, “The problem can be as simple as trying to watch a TV show clear to the end.” Then he adds, “All in all, it’s not been that difficult.”

People are curious about how my parents have managed all these years. They quiz Dad and tell him, “You’re doing a wonderful thing.”

“It’s not a wonderful thing,” he

replies. “It’s a thing that life presented to us. There are all kinds of things that inhibit people. It just happens that this is ours.”

As my siblings and I were growing up, my parents never wanted Annie to be a burden to the rest of us. We all knew how to feed and care for her.



Jerry Smith tenderly places Annie in her bed. Although Annie is unable to talk, her happy smile says volumes to her father.

Occasionally, we still look after Annie as we did when we were younger. But my parents continue to care for her primarily by themselves.

Most of the time, taking care of Annie is simply a part of my parents’ lives. “You think about it to the extent of will we, when we get where we’re going, still be able to handle her?” Dad says. “I feel bad that we can’t fly. I would like to have traveled. I still would like to travel.”

He adds, “There have been times when I’ve really wanted to do something and it just was not practical to do with her. Somehow or other, you either forget about that, or it’s a balance. To care for her is paramount.”

Obstacles at Church

My parents are usually able to take Annie wherever they want to go, although they had to overcome the obstacle of accessibility at their parish church about 20 years ago. At the time, Mom was in the hospital for surgery and Dad had taken Annie to church with him at Holy Angels in Dayton, Ohio, which had not yet renovated to become handicapped-accessible.

Dad had placed Annie’s wheelchair along the side wall, but an usher started to move the wheelchair. So Dad moved Annie to the back of the church and

placed her wheelchair along the back of the last pew, where there was more room for it. The same usher came back and tried to move Annie’s wheelchair again.

Dad got upset and left the church with Annie. They got in his van and he drove around until the next Mass, when he was able to place Annie behind the last pew without incident.

The pastor, Father Joseph Goetz, had witnessed the episode. After Mass, he approached Dad and asked about it.

Not long afterward, Holy Angels opened up one pew in the front of the church to accommodate wheelchairs. Eventually, the remaining two front pews were also opened up and a ramp was built.

Now Annie goes to the 8 a.m. Mass every Sunday with my parents. Dad says, “I thought we needed to go as a family. She’s just another parishioner.”

One Sunday when Mom wasn’t feeling well and Annie stayed home from church with her, Dad recalls that half a dozen people asked him about Annie because they always sit in the front pew.

Mom says, “A lot of people have to see her pretty often before they get enough courage to come up to you and say something or ask you a question.”

Future Concerns

People often want to know what will happen to Annie. Dad struggles with his words and his voice cracks as he says, “The biggest fear I have is when we are not around to take care of her, that at least she gets reasonable treatment because I don’t ever want anybody to hurt her.”

This issue worries Dad, but Mom says she doesn’t think about it much. She admits it may be a “head-in-the-sand thing.” But, she notes, “So far, we’ve handled everything as it’s come along, so I think that everything will turn out for the best.” Mom believes that means leaving what’s going to happen up to God.

I tend to agree with her philosophy. The future still is a big and scary thing. But not being able to foresee it, our family will have to do what our parents have done all along. We will simply have to solve each problem as we come

to it. We have a good example to follow.

When Annie was initially diagnosed with extensive brain damage, my parents followed the recommendations of the doctors: They brought Annie home and loved her.

Mom reiterates the fact that, at first, Annie was a baby. She wasn’t any more trouble than any other baby, once her seizures were controlled with medication. “Babies have to be taken care of,” Mom explains. “We never stopped—just kept on going.”

She recalls what people sometimes say to her: “I don’t know how you do it. I couldn’t do that.”

Then she looks me in the eye and repeats what she tells them: “Oh, yes, you could. Yes, you could.” A

Christine M. Grote earned a B.S. in chemical engineering from the University of Dayton in 1979 and then a B.A. in English from the College of Mount St. Joseph in 2007. Her article “Mary Beth Peters: A Heart for the Poor” was published in *St. Anthony Messenger* last February.