Commentary

The Right Way to Go

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There was great joy in the family when Deborah Kay came crying and kicking into my waiting hands late one night some 30 years ago this month. Two teenaged brothers and a 13-year-old sister knew they would now have a baby sister to play with.

For the baby's 40-year-old mother, the past nine months had been filled with mixed emotions. Nor had it been an easy time for the father. Well into their middle life, with three teenagers in the household, the couple had long ago put aside any thoughts of possible pregnancy. Contraception had been hit-or-miss. And they had missed. The pregnancy test had been positive.

At first there was anger and then panic. Husband accused wife; wife harangued husband. What would friends and relatives say? What will our kids think? Obviously, abortion was out of the question.

Slowly frustration gave way to resignation and then even to guarded happiness. Maybe a Higher Power meant them to have one more "bundle of joy." The teenaged boys, when Mom and Dad finally found the courage to tell them, shrieked, "Hey, that's cool!" The 13-year-old sister was jubilant, "I'll be the babysitter!"

Now, at long last, the day of deliverance was here. With the mother cared for, I turned to the new baby girl. She was chubby, a little puffy, with the hint of a different look about her. But newborn babies, with their molded heads and their squeezed faces, are anything but pretty. Anyhow, she was alive and well, with an Apgar of 8 to 9. I would check her over more carefully on morning rounds. It was 2 AM and maybe I could catch a few winks.

"There's something peculiar about this little one you delivered this morning, Doctor," was Nurse Joan's comment as she brought Deborah Kay to me to examine. Sure enough, the baby's face was still puffy and there was something about her eyes: slanted and almond-shaped. The nose was flat and there was a tiny split in the tip of her tongue. Her fingers so stubby, legs so lax—surely we had to give serious consideration to a diagnosis of Down's syndrome.

Joan made the natural agonized response, "Oh, no, what will we tell the mother?" "Well," I said, "first of all, we won't make any statements until we are absolutely certain of the diagnosis. And, second, let's make sure we use the proper name: 'Down's syndrome,' not 'mongolism.'"

As we expected, all the tests confirmed the diagnosis of trisomy 21, that birth defect caused by one little extra 21st chromosome in mother's egg. Now I would have to face Mom and Dad with the bad news.

It was not easy. After I had finished telling them that Deborah Kay would have these defects, that she would be mentally retarded and that she would live a life of utter dependency, there was only tearful silence. Then . . . "You're very, very sure, are you, Doctor?" asked Mother as she cradled her infant to the warmth of her breast. I explained all the different tests we had used to arrive at the final diagnosis. Hurrying on, I suggested that in instances such as this, parents often decide to place these little ones in institutions, and that this would be a choice they would be entitled to make.

Mom and Dad looked at me in bewilderment. "Doctor, do you know what you are saying? This is *our* baby. No way will we give her up!"

So it was that Deborah Kay went home into the loving arms of a family welded together by the need to cherish and care for and protect this little person, who would live her life in perpetual childhood, never attaining true womanhood.

Bringing up Debbie was not always easy; her mental and physical inadequacies called for special efforts and lots of patience on the part of every member of the family. As an infant she clung to breast-feeding until she was a year and a half. Mom drew on her reserve strength to give the little one the security of her bosom. Teaching Deborah to eat with a fork and spoon went slowly; fingers seemed to work so well. On the one hand, personal matters such as toilet training and perineal hygiene were treated with exasperating indifference by this young lady, while, on the other hand, the first menstruation was a terrifying experience: "Mommy, am I going to die?"

Because Debbie was slow and awkward, other children would laugh at her, taunt her, run away from her. As a result brothers and sisters and Mom and Dad would set aside time to be her surrogate playmates. In return, over the years she showered them all with her smiles and hugs and with those funny, babbled sentences. More than that, she gave them a most precious reward: total devotion, limitless love. And with that the family was given a sense of fulfillment at having accepted the responsibility for the complete care of another human being.

Just last week Debbie and her 43-year-old sister came in for their routine physical examinations. As always, the word was, "Debbie gets to go first." And once again Debbie twinkled her charming, tongue-between-the-lips smile at me and trustingly lay back for her complete examination.

At last year's checkup I had noted an enlarged uterus, and because her extremely heavy periods had resulted in a secondary anemia, we had given some consideration to doing a

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hysterectomy. Today I found the uterus had diminished in size, and sister reported that the periods had stopped completely. Nature at work.

The rest of Debbie's examination showed only the evidence of advancing years—the thinning of her skin, the atrophy of her breasts, the further loss of height, the "widow's hump."

How ironic it is, I thought, as I went through a similar examination of her older sister, that here today is the teenager who at age 13 had happily promised to be the new baby's "babysitter," and who through the past 30 years had been just that, even after she had married and reared her own family.

Yet here was stunted Debbie, whose body I had been privileged to look after as she went through infancy, puberty, the middle years and now menopause, in a span of only 30 years. Here was a person whose entire being had been imprisoned in a fruitless childhood. But during those years what blessings of togetherness she had brought to this fine family as they nurtured her and protected her. How fortunate it was that 30 years ago Mom and Dad had made that wise decision to take her home.

Having finished the afternoon appointments, it was time to lean back, stretch my legs and let my thoughts roam, reviewing the patients and the problems I had dealt with that day. Especially vivid was the vignette in which Debbie had played the leading part. In my mind I tried to transpose the events of 1957 into circa 1987. Had the 40-year-old pregnant woman come into my office today, instead of 30 years ago, how would my treatment have differed?

Obviously, in this day of enlightenment, that intelligent lady would be well aware of the possibility that the embryo she was carrying in her uterus might be defective. She would know also that I, as her physician, would offer her the option of having an amniocentesis done and that she might then be offered an abortion.

For me the specter of professional liability would have hovered over my head. What if the test failed or proved inaccurate, or what if the amniocentesis inadvertently caused the disruption of a normal pregnancy? Surely, if the pregnancy were to be allowed to continue, the weight of uncertainty would weigh upon me right up until the time of delivery.

Would these two people—husband and wife—who were beginning to feel great joy at the prospect of having a treasured "late-in-life" baby, now have to suffer the anguish of making a decision, one that might plague them all the days of their lives, whichever course they chose?

Right now it was easy for me to say that the way we went back in 1957 was the right way, having seen Debbie's life unfold in the tender embrace of a devoted family. Moreover, 30 years ago the choices were not that hard to make; Debbie's parents knew there was just one way to go. Today the way is strewn with sharp stumbling blocks. Debbie's embryo would be the concern, not only of the parents and the doctor, but possibly of the courts, the legislature and the bioethics committee.

Today, why must it be so hard to know—the right way to go?