

How Many Children Do You Have?

By Jere E. Yates

As a child reared in the church and even as an adult, I never recall hearing anything about the disabled and their parents, either from the pulpit or in class. Oh, I have heard in prayers the expression “help the sick and afflicted,” but I have never really thought about who these afflicted were until . . .

On November 8, 1970, my first son, Kevin Jeremy Yates, was born. Inexplicably, his lungs did not fully aerate, and thus he suffered brain damage. The diagnosis and the prognosis were not complete until he was four months old: spastic quadriplegic (cerebral palsy), with no hope for being normal.

This frequently asked question, “How many children do you have?” deeply disturbs me. I actually have three children including Kevin; but when I say “three,” other questions follow, such as “Do they get along?” “Do the two brothers fight?” Do casual acquaintances really want to know about all of my children? I suspect not because when I do reveal the fact that Kevin is disabled and does not live at home, they appear to get quite uncomfortable. Perhaps I make them feel ill-at-ease by my tone or the way I answer. I try to be matter-of-fact, but sometimes I am aware of a more emotional tone taking over in myself. If my tone changes—or even if it does not—I worry that the person will believe I am asking for sympathy.

I honestly do not do this because I am seeking sympathy, but rather my change in tone is a result of the difficulty I have in controlling the rush of my feelings to the surface. Some people will respond with such a display of pity as to make me regret having mentioned it. Sometimes I respond to the questions about my children without mentioning Kevin, and then I feel guilty for leaving him out, even though I know there are some practical reasons for it; then I chastise myself for taking the road of convenience and practicality.

How Is Kevin?

Some who know Kevin do occasionally ask about him, but most do not. Why? Is it because they are uneasy in asking or because they are afraid I will become emotional? I suggest that it is both. It appears that both sides feel more comfortable not mentioning the fact of his permanent disability. Some parents are reluctant to take a disabled child or person out or to invite friends in to see him or her because they do not want to make others feel uncomfortable. The parents may also fear their inability to handle their emotions in the presence of others.

At times, I have a need to share my son and my feelings about him with close friends, but I usually resist for fear of imposing my burden on them. I know we are supposed to “bear one another’s burdens,” but this one seems too heavy to share and to expect others to bear. Yet how can one be a truly intimate friend and not share the totality of life?

People seem to know better how to comfort the bereaved following a death in the family than how to respond to the ongoing, agonizing struggle parents face with a disabled

child. ... The disabled child continually presents new problems to parents, taxing their coping mechanisms. ... I confess that I block Kevin out of my mind much of the time. I do it out of necessity because the constant load of worrying about him would be too distressful to endure.

Have You Ever Wished He Had Died at Birth?

A few individuals have had the courage to ask whether I have ever wished that Kevin had died at birth. The answer is yes, I have. For a number of years, I thought everyone, including Kevin, would have been better off if he had died at birth. But now I have a different perspective. Kevin's charming smile and genuine responsiveness to people have warmed the hearts of many individuals and deeply touched lives for good in ways that most of us could never do...

In addition, he provides a real opportunity for people to learn the meaning of service and to appreciate their own abilities, which they may take for granted. To wish he had died is to be selfish—it is my seeking to avoid personal hardships at the expense of denying him the pleasures of living...I am convinced that in mysterious ways God has worked through Kevin to bless many lives over the past eighteen years.

How Often Do You See Him?

Kevin lives twenty-five miles from home, and frequently I am asked the question, "How often do you see him?" I feel more guilt about my response to this question than to any other because I do not see him as often as I would like or need to. I usually reason, or perhaps rationalize, that I have obligations to my family, my work, my church, my friends, and myself as well as to Kevin. It is not easy to bring him home; it is hard both physically and emotionally.

Because I know he receives good care and personal attention where he is, I find it easy enough at times to neither visit him nor bring him home.

Was It Difficult to Place Him?

We kept Kevin at home for three years before making the difficult decision to place him. To say the decision was arduous is an understatement, yet in a strange way we had no choice. We (felt) we had no choice if we valued each other, our other children, and Kevin himself. Professionals and other parents in similar situations were one hundred percent sure that placement was the right choice. We heard stories of parents who had tried to keep their disabled child at home for years, only to learn later—after divorce, after their children had suffered emotional problems, and after their own physical ailments surfaced—that placement would have been best all along. Considering all these factors made the rational choice easy, but it did nothing for the emotional trauma I suffered upon leaving Kevin for the first time...The first few years were truly years of adjustment for all of us. Kevin would cry his heart out every time I would leave after a visit at his "special home" or at our family home. Those times were excruciatingly painful for me...

Do You Blame God?

Perhaps I have repressed any thought of blaming God for Kevin's misfortune, but I do not think so. I cannot explain why, yet I have never accused God of causing this tragedy. The classic problem of theodicy (if God is good and all-powerful, why does He allow evil?) has stumped most of us, though some ideas have helped me. The ultimate answer for me is the same as the answer given to Job—a childlike faith. Because I have only finite understanding and perspective, I do not know why God would allow this tragedy to occur. Perhaps Kevin and others like him have been placed here to teach us the true meaning of ministry to one another; perhaps to manifest the hidden goodness in people that a disabled child can bring out; perhaps to cause us to appreciate our normal functioning as contrasted with a helplessly disabled person; perhaps to strengthen our dependence upon God; perhaps to give meaning to the idea of anguish; perhaps to remind us that justice is not to be achieved in this life; perhaps ...

If Kevin's situation worsens in the years to come, I may feel angry toward God; but at the moment, I get some consolation in recognizing that Kevin's ultimate fate is in His hands, and I trust Him. My theology leads me sometimes to dream of being with Kevin in the afterlife when he's fully functioning and to dream that I will know of his thoughts and feelings regarding our decision about him in this life. How wonderful it would be to hear him say we had made the right decisions; how dreadful if he saw it otherwise! I would give anything to have real communication with him now, but alas, I shall have to settle for then.

How Many Children Do You Have?

This question with which I began causes me to reflect on what I really need from others. I believe I need other people to deal with the total me. It is acceptable to be awkward in showing an interest in Kevin or in how I am handling the difficulties of being the father of a severely disabled child. To accept my discomfort in dealing with the very tender feeling generated by talking about Kevin is also what I need from friends. Above all, I do not want Kevin's disability to be a major handicap for him, for me, for my family, or for my friends.

Given Kevin's childlike qualities—innocence, genuineness, spontaneity, love, trust—and the fact that my other children will grow up to be fully functioning adults, viewed from the perspective of a lifetime, perhaps the answer to the above question is "I have only one child, albeit a very special one!"

Truly, it is a poignant article to which many secondhand sufferers can surely relate. It feels hard for me to read in retrospect, but it helps to understand what my parents were going through. Now, many years later, I have noticed a new phenomenon with my dad, and he has also just refreshed this article with an update at age eighty-two. He notes the following:

It has been thirty-five years since I wrote my article about Kevin. Having reread it several times recently, I don't believe I believe any differently now than I did then. Some things have changed but my answers to the questions I raised in that article have not.

One change is rather monumental. Several years after Carolyn, my wife of fifty-one years, died, I realized that I was grieving more about the tragedy of Kevin's situation than I had for years. In reflecting on why this might be, I believe I found the answer. Carolyn always believed deep down that she did something in her pregnancy that caused Kevin's breathing problem at birth. After extensive examination by attorneys who had previously been practicing physicians, I was convinced that she was in no way responsible; it was an accident with no attributable cause. Because of her belief, she was very uncomfortable being around Kevin for long periods of time.

I always felt that I had to be strong emotionally lest I adversely affected her, leading to an emotional breakdown. With her being gone and my daughter stepping in to deal with issues connected with Kevin's care and health, I realized that I was allowing myself to grieve more than ever, though I still did not let myself dwell on it for long. Knowing something about stress management, I never allowed myself to focus on his situation very long. My major way of coping became one of blocking out thoughts of him after a short period of grief. I have always reasoned that my being emotionally "down" about Kevin's situation did not help him or me.

The other major change is that I no longer hesitate to mention at a social event, when asked about the number of my children, that I have **THREE** children. I freely identify that one of my children is special because of his disability. I am much more comfortable sharing about his life without worrying about making people uncomfortable when I identify his disability.