

The Life-Prayer of Special Parenthood

If you came this way,
Taking any route, starting from anywhere,
At any time or at any season,
It would always be the same: you would have to put off
Sense and notion. You are not here to verify,
Instruct yourself, or inform curiosity
Or carry report. You are here to kneel
Where prayer has been valid.

T.S. Eliot, *Four Quartets*

Journeying with a multiply disabled child is a life-prayer. We kneel with those who have come before us on the journey *where prayer has been valid*. And prayer, as we all know, is prayed in the midst of all life experiences—joyful, sad, anguishing, exhilarating, pensive—through uncertainty and pain, through gratefulness and resignation. The prayer-journey itself is always the supreme quest, challenging us to grow and ever beckoning us to immerse ourselves in the mystery of creation itself and, for us, in the life of our child, the gift of the Author of that creation. Thus, we delight in the silent milestones that only we can fully appreciate—whether they are the first suck of our disabled infant on a bottle, a first step by our child after a long convalescence in a wheelchair, a first name scrawled by our child over an entire sheet of paper. We learn to take little steps with our child and to delight in them. Prayer teaches us that apparent, transitory successes do not measure our prayer’s validity, but rather our faithfulness to the journey itself does. And the journey, for those of us who have raised a disabled child, is worth taking, worth embracing—worth living for a lifetime. Other voices from a cosmetic society would belittle our journey, but those voices have never known the supreme beauty of learning lessons from our child that are life-transforming—lessons that all lives are sacred and valuable, that we are enabled to embark on our quest by the good God above, that we are invariably linked to a world beyond tangible gain, material success, and godless self-sufficiency—to the kingdom of heaven itself.

My son Christopher was born twenty-three years ago on a blustering January evening after a traumatic birth and delivery that robbed him of normal intelligence, strong

muscles, and emotional stability. Christopher had contracted beta-strep in my womb, and a scenario of deflated lungs, infection, sepsis, and five weeks in a neonatal facility on 100% oxygen would eventually leave him mentally retarded and crippled for life. There had been shadows in my pregnancy in which I had feared his inevitable fate—I had toxemia and was hospitalized eleven days prior to his birth and I had been on some pretty potent anti-depressants during pregnancy to combat my depression. And now God was asking me to trust Him and to take care of this child when I could barely care for myself. I had been blessed to have a very supportive husband, but he worked 16 hours a day just to make ends meet. And there was so much uncertainty. Would I be able to get Chris to suck on a bottle? Would he be so handicapped that he would need institutional care for the rest of his life? But God was merciful and loving. He showed us day by day the path we should take to care for his needs and not to anticipate the Big Picture. Slowly we would learn of his debilitating conditions—they unraveled through the years like a tapestry fraught with joy and sorrow, hope and fear, but they unraveled slowly so as not to be overwhelming. True, we learned he had problems with his legs at age seven weeks when they would not respond to a therapist's promptings. While he smiled at us often, he would not say his first word until he was four. About that time he began using crutches. His first word was "O.K." He especially liked McDonald's French fries, so I would get him to walk out to the car with his crutches, place him in a car seat, and ask him the question if he wanted French fries just to get that little word out of him. During our very warm summers we expanded to "Christopher, would you like an ice cream cone?" Such small, but welcomed steps.

One of the greatest spiritual lessons God taught us with Christopher was that often, no matter how dear he was to us, that we had to be willing to surrender his fate to the loving Creator. This surrender occurred quite frequently because Christopher would have several serious surgeries during his young life and each time was an ever-new abandonment, a venture into the dark with the hope of good to come. His first surgery was relatively minor as it was a surgery to lengthen his heel chords though the danger existed that if they were unintentionally lengthened too much that his little feet would flip-flop. But the surgery went well and he was able to place his ankles on the ground with the rest of his feet, which improved his walking with crutches. Other surgeries were far more dangerous. He would have an experimental back surgery, known as a rhizotomy at NYU's Medical Center in Manhattan, which lasted nine hours. His young body quivered much during the first agonizing hours after surgery, but that time past and he spent three months in rehabilitation. His spastic legs, tightened by his brain damage, loosened considerably, which likewise improved his ability to walk with crutches. At age nine a hip surgery would not be as successful, confining him to a wheelchair. But God looked after his little spirit and he grew in grace, love, and tenderness of heart. We always knew we were blessed to have this child near us—he taught us dear lessons about suffering and resilience that have taken us through difficult family times and renewed our love for one another.

When he was about twelve, I began thinking about his future. Gordon and I would have loved to have had other children who might have been able to look after him once we deceased, but God only gave us this special little one, which was really all we could handle. Christopher had some first cousins, but somehow I knew that God had something else planned for Christopher. He was such a spiritual child and I wanted him to have access to the Eucharist and priestly counsel. I began to be troubled in spirit because our Diocese did not have a church-related home for the handicapped in our city. I approached our pastor about starting a facility, but he spoke about elaborate proposals, which I did not have the talent to put together. For several years, my mother's heart tried to convince myself that everything would be ok. Little did I know how beautiful God would resolve this for us. For interior strength I repeated the Psalmist's song: "The Lord hears the cry of the poor; blessed be the Lord."

Time passed. Christopher entered a Special Ed High School Program, and, at first, he flourished. Then, some changes in school personnel, however, led Christopher to begin experiencing anxiety and depression in the classroom. He was often very sad upon leaving for school and he began having incontinence issues in the classroom. We decided to withdraw him from school. He developed a hobby of watching Star Trek episodes on TV at home and we began getting him Jean-Luc Picard dolls, Kleons, etc., along with Star Trek model battle cruisers. He became immersed in this imaginary world and became content again. We moved 70 miles away so that I could take a job with Social Security with the hope that we would be able to afford a trust fund for Christopher's future care, and for a while life settled into a predictable pace. The job did not work out, however, and we were in a new place without the support of family and friends. But God was always there blessing our endeavors, holding out his Hand to us, even through the most excruciating of realizations that perhaps someday Christopher would be without someone to advocate for him—without the sacraments themselves because he would just be one more vulnerable and incoherent voice in a nursing home or institution before he was even old. This latter realization produced such a helpless internal scream within me that I sometimes could not bear. So I decided to do something about it. Through a nearby church I was able to train as a Eucharistic Minister, and then God placed in my heart to reach out to the handicapped in South Carolina.

I had to trust God to take care of my son, but I was able-bodied enough to make a difference in someone else's life even if it were for a short time. I decided to visit the Catholics in a mentally handicapped institution in my home state of South Carolina, giving the Sacrament to those who were able to receive the Lord, and just be there as presence for those who could not. One young man, about my son's age, I remember quite well. He moaned a lot—his need for human companionship was so great and his utterances so desperate that I knew without question that I was in the presence of the Crucified Lord. That experience was life changing for me. I held my own son a little closer for a long time and thanked God that he had enabled us to care for him, trusting Him that He would direct us to the best place for Christopher's future care.

Since then, other life-changes are imminent. As we speak, my husband qualifies for early retirement in a few months. Last August, my husband and I celebrated our 25th wedding anniversary at Belmont Abbey Church—the church we were married at and which is affiliated with our *alma mater*. The priest who married us mentioned then that the Sisters of Charity, who used to operate the sister college to Belmont Abbey across the street, still operated a home for the mentally handicapped. He would be happy to write a letter of recommendation for us—the initial step to the fulfillment of a lifetime dream. And so the journey begins anew. Thanks to him, in a few years we will move to the Belmont area so that Christopher can be put on a waiting list to be serviced by the Sisters and their staff. This time is especially good because the home is anticipating new growth. We are filled with hopeful anticipation.

I realized by now that I was truly blessed. I had an innocent child to continue to raise—we would be able to be just as proactive in his care even if he were accepted into the home. Too, the blessing extended to my realization that he would never offend God—he was a living saint. He rarely complained of his disabilities trusting in God to give him a new back, brain, and legs when “we came back to life again” on the Last Day. The priest who married my husband and me repeated the angel’s prayer to Mary for me and asked if I would meditate on it: *Blessed are you among women and blessed is the fruit of your womb*. I knew he didn’t mean that I was being compared to Mary’s “yes” or I in any way possessed her goodness; rather, I was completely blessed to have a child so dear to the heart of her Son. Since that time, I have tried to grow in patience with well intentioned others who saw me carrying a cross, that I knew in my heart of hearts was sheer blessing. Christopher was that blessing beyond blessings and I could never live without that beatitude in my life or that source of virtue. Amen!