The Chink for That Mysterious Ray of Light
A Theology of Disability

Jo McGowan

The author, a mother of a severely disabled child and daughter of a mother with Alzheimer's disease, considers the truths she has learned from loving and caring for her child and parent. She finds that a different way of viewing and understanding life has been given to her by the ongoing encounter with the suffering, weakness, and limitations of people she loves.

People come to Mass every week with their own lives very much present to them. Although most believers make an effort to submerge themselves in the sacrament and be present to the miracle taking place, the reality of home, family, work, and friendships keeps insisting on being acknowledged. While it may seem that people are distracted, especially when listening to the homily, unless faith is grounded in the stuff of everyday life, it is not sustainable. How we deal with divorce, illness, sudden wealth, success, death, the loss of a job, or the birth of a child has everything to do with what we believe. And with the help of the Mass, prayer, Scripture, and spiritual guidance, we work out what we believe in the constant and ever-changing testing grounds of our own lives.

When I sit at Mass, my mind is often preoccupied with thoughts of my eleven-year-old daughter Moy Moy, who has a degenerative disorder which has given her a severe mental and physical handicap. When her difficulties were first diagnosed, I tried to prepare myself for what I thought would be a drastic narrowing of my life's possibilities. I had no idea that, to the contrary, my life was about to take off; that, far from shrinking, my horizons would expand beyond my most ambitious dreams.

Jo McGowan, a well known writer, has a regular column in Commonweal magazine.
A Second Chance

Disability is a strange phenomenon. It can be a stone wall, blocking the sun, preventing movement, keeping one captive; or it can be a total turn-around, a chance to try another road entirely, a new life. It was the second for me, both in actual, day-to-day terms and, more importantly, in my spiritual life and my search for God.

The actual, first, since it is easier to explain. I live in India, where schools for children like my daughter tend to be gray, dreary places, holding areas more than anything else. Unwilling to send her to any such place, a few friends and I started a school ourselves. I am now the director of it and it has become the center of my existence. Although I do not work directly with the children—I have hired professionals for that—I am responsible for fundraising, networking with other organizations, awareness raising, and administration.

I meet parents every day, many of whom are just starting out on the journey toward acceptance of their children. I deal with public attitudes toward disability which were common in the United States some fifty years ago—all of our worst fears and lowest thoughts can be found here without apology: people stare and point and make unkind remarks. Accessibility is non-existent—if I take Moy anywhere, I must make complicated and arduous arrangements. If I didn’t have a car, as most of the parents whose children attend our school do not, I would go almost nowhere.

Freedom to Choose

Against this unlikely backdrop, my spiritual life has developed and deepened in ways I could never have anticipated. It begins with the choice that one is given at the outset (and every day—the beauty of a life of faith is that a new choice can be made at any time): to accept one’s circumstances with joy, as a blessing, or to reject them as a curse and to feel resentful and hard done by. That this is, in fact, a choice came to me gradually. I did not see it as such to begin with. But as parent after parent came to me in the school feeling overwhelmed by what fate had dealt them, I began to realize that it is up to us to “choose life” or to reject it, and that the choice itself has transforming power.

Once the choice is made, many other things fall automatically into place. The care of a child with disabilities, for example, can take up an astonishing amount of time, time that is difficult to account for as so little seems to have been accomplished. If the choice made has been one of acceptance, however, the time spent is prayer.

What is prayer after all? It is the praise of God, and how better to praise God than to care for one of God’s children, especially if that child is one whose life
has no obvious utility. Moy Moy will never be a productive citizen—even in a sheltered workshop, she will never be able to hold a job. There are those who would say she would be better not having been born in the first place. But thinking about that argument brings us to reconsider our own place in the world and how we justify our existence.

**Justifying Our Lives**

Are we allowed to be here because of what we can produce? Is our presence tolerated because of our contribution to society? Do we become less valuable as we grow old, or when we are ill, even if temporarily? This kind of a philosophy is one most of us would not be prepared to accept. It is not even practical, as everyone has days of illness and incapacity, even in a highly productive life. Nonetheless, some element of this reasoning is present in our commonly held attitudes. We have contempt for able-bodied people who just do not feel like working. And yet, we would not agree that it would be right to kill them because of it. Clearly, there is something beyond mere utility which determines our worth.

Caring for a child with a disability sharpens that awareness in surprising ways. Habit is at the core of it. With Moy Moy, for example, we have a daily routine of bathing, dressing, feeding, and exercising. Many acts which would seem strange with another child, like the constant wiping of drool or the arranging of her limbs to avoid the scissoring her legs automatically assume, are unconscious for us in our care of her. But in repeating them over and over again, dozens of times each day, we are enacting our belief in the value of her life as it is: with the drool, the incontinence, the rigid muscles, the lack of traditional intelligence. With a baby, we do many of the same things, but with an underlying expectation of how she will be; with an elderly parent, there is a memory of how he once was. But with a child like Moy Moy, there is only the present. This is how she is and we accept it.

**Acting the Part**

Even if we do not think that we do accept her, even if we doubt the value of her life in our secret inner souls, we act as if we were certain. We dress her and feed her and hold her and play with her and gradually the certainty comes on its own.

In a similar way, we do not need to believe in the Eucharist each and every time to still experience its power when we receive. Often, simply getting ourselves to Mass is the best we can do. We go through the motions, devoid of any real conviction, save that this is an obligation we must fulfill. And the act itself carries us forward.
Going to Mass and saying our prayers, however, are more voluntary than the care of a child. We do not have a choice about whether to feed Moy Moy or whether to give her medicines. We may miss Mass occasionally or forget to say our prayers, but a child must be fed. The effect, therefore, occurs whether we wish it or not.

**Counting Our Blessings**

I have often observed a spiritual depth in parents of children with disability which is lacking in parents of able children. This is not to idealize disability. For many it can be disastrous spiritually, driving them to despair. But seen rightly, I believe it is an opportunity for spiritual growth which is quite unlike any other. Because, however painful our child's handicap may be, both for us and for her, at the center of our experience of it are the love she inspires in us and the dailiness of its expression.

Why are we here on this earth? It is one of the most critical questions we ask ourselves and, given our human tendency to believe ourselves more important than we are, our answer would seldom be anything as pedestrian as the care of one child.

But why not? Would we shun the care of the child Jesus as unworthy of our time? Yet he himself said that when we welcome a little one, we are welcoming him. And what else is life about if not the discovery of Jesus in every other being?

Being trusted with the care of a child with a disability changes forever our sense of ourselves. We are both more important—taking care of Jesus!—and less—changing diapers, spoon-feeding an eleven-year-old—than we could have imagined. And as we see ourselves anew, we may begin to get some sense of how God must see us.

As parents we probably come closer to the ideal of unconditional love than in any other relationship. Indeed, the love that parents have for their children is used in Scripture as a given to illustrate the still greater love of God for God's creation: “What man of you, if his son asks him for bread, will give him a stone? Or if he asks for a fish, will give him a serpent? If you, then, who are evil, know how to give good gifts to your children, how much more will your Father who is in heaven give good things to those who ask him!” (Matt 7:9-11). Also, “Can a mother forget her baby? Or a woman the child within her womb? Yet, even if these forget, I will never forget my own” (Isa 49:15).

But even when our love comes close to being unconditional, it is seldom without expectations. No one is capable of disappointing us more than our own children. No one else's faults hurt us quite so much. When a child has a disability, however, we seem to be out of the business of expectation. It may not always be
the best thing for the child—disabled kids can be spoiled just as easily as able ones—but as a way of loving, it is instructive.

It mirrors, I believe, the pure love God has for us—a love which is truly unconditional in spite of God's clear-sighted and unsentimental view of our deepest selves. In that view, *we* are the ones with the disability, *we* are the ones who must struggle to overcome the handicap with which we were born.

I like this image of God as the ultimate Special Educator—the one who comes to us early and late, encouraging our smallest efforts, leading us on to the next step, picking us up when we fall—but it was Moy Moy who revealed it to me.

**Zen Baby Master**

Indeed, without her as my touchstone, I do not know where I would be. A Zen teacher once instructed his student to “show me your original face.” Moy Moy’s original face is the only one she has, and I think of her as my baby Zen Master, as a channel for the purity of life to express itself.

I am most conscious of it when she stares at me. Never having been socialized to realize that there is an allotted time after which you must avert your eyes, Moy Moy stares openly and calmly and, although her intellectual development is said to be that of an infant, it is impossible not to acknowledge the spiritual depth in her gaze. As one friend put it, “she looks straight into your soul.”

**The Gift of Silence**

My soul. It is not always easy to search it, even with as nonjudgmental a companion as Moy Moy. But search is the wrong word for what I do with her—it is too active, too busy . . . she who is without words is, in fact, beyond them, existing peacefully in a realm of nonintellect where soul-searching seems frantic, obsessive. With her, I have learned to stop asking so many questions, to enjoy silence and stop feeling so strong a need to speak.

This is a major change in my life. Conversation is my favorite sport, reading my favorite leisure activity. I love words and I thrive on intellectual engagement. To learn how to relate on a basis in which the mind is completely irrelevant has been challenging, but curiously refreshing. After a full day of talk, talk, talk, it is a relief to come home to Moy Moy who smiles and says nothing. When my other two children return from school, they are full of stories, eager to tell me every last thing that has happened since they last saw me. And while I am grateful to listen (teenagers do not always want to talk to their elderly mothers), there are times when I would welcome some quiet.
The Russian Orthodox theologian Alexander Schmemann expressed a similar conviction in his journal. Reflecting on his busy, vigorous life of teaching and lecturing, he said:

Maybe that is why I love an empty church where the church speaks through silence. I love it before the service and after the service. I love everything that usually seems to us to be in between . . . that which may not be important but which, it seems to me, is that chink through which a mysterious ray of light shines.

For many people, Moy Moy’s whole life is an in-between, an intangible non-entity, neither truly alive nor truly dead, just hovering in limbo, waiting to be released. I am not belittling this view. It is the common one and it is understandable. We value the mind too much to know what to make of a life like hers where the mind seems empty. We value free will too much to know how to make sense of a life where will of any sort is meaningless. She makes no plans, considers no past, has no expectations, and bears no grudge. We just cannot fathom it.

Mystics and ascetics spend their whole lives trying to achieve the detachment and inner peace that Moy Moy wears as lightly as a butterfly. We marvel at their struggles and admire whatever self-mastery they manage. But we dismiss the perfection that Moy Moy attains because it is “natural,” with no effort involved. We do not do the same with physical beauty or artistic talent or intellectual prowess, however. In such cases we speak of the person being “gifted,” recognizing, in the choice of that word, their good luck.

A Gift or a Curse?

Most of the “gifts” we get in this life come with a hidden price. People who are exceptionally beautiful or brilliant or talented in any way encounter many difficulties precisely because of their specialness. These difficulties are primarily spiritual ones: Pride is a constant temptation in a world which is quick to assign credit for gifts to the receiver rather than the giver.

It is ironic, then, that the one gift which practically guarantees salvation is seen not as a gift at all but a curse, or, at best, a tragedy. While most people, if they thought about it, would agree that a mental disability is a tragedy not for the people directly affected but for their families, this, too, is a strange and short-sighted way of seeing, especially for believing Christians, who know that this world and this life are but a tiny piece of eternity.

Henri Nouwen, the Dutch priest and spiritual writer, wrote his last book about a young man named Adam. Adam had a severe mental and physical handicap and Nouwen looked after him in the group home in which they both lived until he
died at the age of thirty-four. Like Moy Moy, Adam could not speak, suffered from frequent seizures, and needed help with the most basic of his needs. Yet his presence, like hers, was so powerful that many who encountered him spoke of being profoundly moved by the experience.

... encounters with Adam often became experiences of inner renewal because he offered [people] an opportunity and a context to think differently about their lives, their goals, their aspirations. Adam offered those he met a presence and a safe space to recognize and accept their own, often invisible disabilities.

Adam's ministry was unique in that he seemed unaware of all that was happening around and through him because he didn’t know about care, ministry, healing or service. He seemed to be without concepts, plans, intentions or aspirations.

Adam, by his eyes and by his presence, said to us, “Don’t be afraid. You don’t have to run away from your pain. Look at me, be close to me, and you will discover that you are God’s beloved child, just as I am” (Nouwen, 64–65).

The first time I read Nouwen’s book, I thought he sounded sentimental and over the top. There was a limit, I believed, to how much we could ascribe to people with such narrow awareness and understanding as Adam and Moy Moy. We might benefit from taking care of them, and learn something in the process, but the credit for that should really belong to those of us who are reflective enough to analyze the dynamics of the situation and put it into a theological framework.

I still think he sounds sentimental (he loved Adam dearly), but now I am inclined to agree with his conclusions. We are so biased toward beauty, intellectual gifts, and artistic talent that if we see God anywhere, we see God in these. But even more critical, we believe so firmly and so utterly in ourselves that we forget the fundamental truth that it is “not I, but Christ in me.” Or, as Gerard Manley Hopkins put it:

I say more: the just man justices;
Keeps grace: that keeps all his goings graces;
Acts in God’s eye what in God’s eye he is—
Christ. For Christ plays in ten thousand places,
Lovely in limbs and lovely in eyes not his
To the Father through the features of men’s faces.

What a simple thing to believe! And how it would transform our lives if only we could! But nothing is ever so simple, and as Dostoyevsky wrote in The Brothers Karamazov, “Love in action is a harsh and dreadful thing compared to love in dreams.” We do not find it easy to remember that God is present even in our most painful circumstances, nor that God is most frequently to be found in
the most unlikely of people. We may be able to praise God for a Mother Teresa, but for the village idiot? That one we put down to God’s incomprensible ways and leave it at that.

For the past ten years, my mother has been suffering from Alzheimer’s disease. It was a fairly slow progression to begin with, but in the last year she has deteriorated rapidly. Standing by watching helplessly as this brilliant and holy woman has been changed almost beyond recognition has been nearly unbearable for my father and my brothers and sisters and me. The idea that she is disappearing in front of our eyes, that she is here but not here, is too difficult to accept.

Whenever I return to the United States for a visit, one or the other of my siblings usually calls me in advance to try to prepare me for the further changes I will see in my mother. I am going back next week, not having seen Mom for a year, and my sister is sure that I will be devastated when I arrive.

Although I worry that I may seem heartless, however, I don’t think I will be. My experience with Moy Moy has changed forever my understanding of suffering and human weakness. Because her disorder is a degenerative one, we have had to watch her slow regression from a chattering, happy five-year-old to the sweet but silent girl she is today. In the process, we have learned that nothing is ever really lost. We still have that five-year-old; she is the same person in front of us now, existing in one moment of eternity.

And the woman who spent years at the Catholic Worker, published a book and countless articles, married her best friend, and raised seven children with him cannot have disappeared simply because she no longer remembers whom she met just five minutes ago. Nor is this phase of her life any less meaningful than all that has gone before it.

The mystery of human existence unfolds against a backdrop as immense as the night sky. We worry about our own little star, never realizing how vast and limitless are the time and space allotted to us. It was my mother who introduced me to the Indian poet and Nobel Prize winner Rabindranath Tagore. One of her favorite poems had eternity as its subject:

Time is endless in thy hands, my Lord.
There is none to count thy minutes.
Days and nights pass and ages bloom and fade like flowers.
Thou knowest how to wait.
Thy centuries follow each other perfecting a small wildflower.
We have no time to lose, and having no time, we must scramble for our chances.
We are too poor to be late.
And thus it is that time goes by while I give it to every querulous man
who claims it and thine altar is empty of all offerings to the last.
At the end of the day I hasten in fear lest thy gate be shut;
but I find that yet there is time (Tagore, 30).
In that wonderful, expansive view of our lives, we can afford to relax about the small and fleeting anxieties and sadnesses that fill our days, knowing that as large as they seem in the moment, they really are small and fleeting.

**My Prayer**

The prayer that I say most often these days, the one that keeps me anchored and secure in spite of the terrifying specter of my mother's deterioration and my daughter's grim prognosis, is by Reinhold Niebuhr: “Lord, you have made us very small and we bring our years to an end like a tale that is told. Help us to remember that beyond our brief day is the eternity of your love” (23).

The knowledge that Moy Moy's life will probably be very brief indeed, and that my mother's condition will only get worse, makes this prayer almost unbearably poignant. How is it possible to believe in a love that allows so much pain? And yet, sometimes in spite of ourselves, we do. The man we believe in won our freedom and the promise of an eternity of joy through his suffering and death on a cross. He was “a man of sorrows, and acquainted with grief” (Isa 53:3). We can expect no less for ourselves. But just as the cross has been transformed into a symbol of power and resurrection, so can our disabilities, and those of the people we love, become our pathway to God.

**References**


