

An Unwasted Life

When I was hired by the Office of Mental Retardation and Development Disabilities of New York State as a Habilitation Specialist, I was assigned to work in a cottage that housed thirty of the most severely impaired residents. One of the female residents under my care, Myelva (not her real name), had been institutionalized since the age of five due to severe seizures. Her records indicated she was thirty-five years old and a baptized Catholic but said little else about her history, except to report her recent behavioral activity. Due to her seizures she developed a head-banging disorder that caused a hydrocephalic condition: Her head was quite swollen and the flesh was very soft. The seizures eventually caused her speech to become garbled to the point of being unintelligible. Her inability to communicate caused her to withdraw and become isolated from social contact with other residents and staff. She became an angry and aggressive person, causing other residents to avoid her. When she became violent, it took two or three staff members to restrain her until she calmed down.

Due to the many seizures, Myelva lost her ability to walk. When she wanted to go somewhere, she slid to the floor, rolled to where she wanted to go, and then pulled herself up. To move from room to room, she was supported by two staff or rolled in a wheelchair.

In the dining room, she refused any help to eat. Food ended up in her hair, her ears, all over her face; some eventually ended up in her mouth.

It was necessary to replace staff working with her every six to nine months due to burnout or injury. Over time, hundreds of staff members who knew her chose to take assignments in other cottages.

In addition to her seizures and the erratic behavior they caused, Myelva had a very short attention span. When psychologists tried to administer an I.Q. test, she was so uncooperative that they listed her as having an I.Q. of zero. This caused state inspection officials to insist that she be locked up in our cottage. They would discuss among themselves the need for laws to euthanize such people, believing their lives to be of little value.

This was the Myelva I inherited.

Bedtime was a constant struggle: Myelva simply refused to sleep in her bed. Instead, she always fought to sleep *under* the bed. (State regulations require all residents to sleep in a bed.) When staff wasn't looking, she would slide under the bed to sleep, renewing the confrontation. To prevent further injuries to Myelva and the staff, I instructed them to place the mattress on the floor under the bed and to be sure Myelva was covered by the necessary bedding.

I worked with Myelva for five years and gradually built up a trusting relationship, for no one had been able to work with her for this length of time. Eventually, I began to understand her babbling; it was like trying to learn a difficult foreign language. In time we managed to develop a basic mode of communication.

One day I asked her, "Why do you sleep under the bed?" She tilted her head back and gave me an exasperated look, as if to say, don't you know? She replied, "So the devil can't find me." I was awestruck; I couldn't believe what I heard. Where did she get this idea, this fear? Possibly, over the many years, some frustrated staff members made negative comments to her. But how could someone with a reported I.Q. of zero have such a profound feeling? I knew there was more to Myelva than anyone could have imagined.

On my way into work every morning, I would stop and have a cup coffee with the Catholic chaplain, Fr. Gallagher. One morning he told me that the bishop was coming to confirm a few of the residents from other cottages. I told him I had two Catholic clients, Myelva and Freddie, who should be confirmed. We contacted the bishop and asked his approval to include my two clients. He agreed. The staff chipped in and bought Myelva a beautiful white dress for the occasion.

Knowing what a short attention span Myelva had, I waited until the last possible moment to wheel her into the chapel. Unfortunately, the bishop was a half hour late. Myelva became upset, started to lose her composure, and began ripping her clothes off. I rushed her back to the cottage and quickly returned to the chapel to be with my other client.

After the ceremony, the bishop asked me about Myelva. I explained to him what had happened and he said he would come to the cottage to confirm her. I called ahead to the cottage and had the

staff get her cleaned up for the bishop's arrival. Myelva was confirmed that day.

My schedule called for me to have three weeks of dayshifts, followed by one week of nightshifts. Shortly after the confirmation ceremony, the week of my nightshifts arrived. Making my rounds, I found Myelva sleeping in her bed. I was surprised and complimented the staff on duty. "How did you do it?" I asked one of them. She replied that she didn't do anything — Myelva just got into bed by herself. Every night from then on she slept in her bed.

When I went back on dayshift, I asked Myelva about the change: "How come you are sleeping in your bed?" She gave me a quizzical look and simply said, "The devil can't touch me now."

Her simplistic comprehension of confirmation was striking. I was astounded by Gods' grace and the power of the Holy Spirit. There was a distinct sense of peace about Myelva now.

Sadly, three months later, Myelva choked to death during a seizure and died in her sleep. Staff tried to revive her with mouth-to-mouth resuscitation, but to no avail.

Normally, when a resident dies, only the staff and members of that cottage show up for the funeral. At Myelva's funeral, however, the chapel, which seats five hundred, was overflowing. Fr. Gallagher, looking out on the large congregation, said to me, "Deacon, you knew her best. You are preaching!"

When it came time to address the impressive gathering, it struck me how many lives were touched in a positive way over the years by having been associated with Myelva in one way or another. What had we learned from our experiences with her? The first thing we learned was a deep compassion for a person whose soul was locked in the solitary confinement of her infirmed body. We learned to practice patience when feeling impatient. We learned to forgive our hurts and injuries as she could not be held responsible for her propensity to react violently. We learned true empathy, to personalize her feelings and apply them to other members of the cottage, which made us better caretakers. In her "nothingness" she influenced us to be better people.

The only gift Myelva received from God was life, and very little amenities that go with that life. Yet, in her misery, she made us better people for having had the opportunity to know and work with her. We knew her as a caterpillar. I pray to have the opportunity to see her in Heaven as a beautiful

butterfly. Her life was not wasteful or pointless, for, because of her, we all experienced a metamorphosis of attitude and received special gifts that helped us treat one another, and especially the disabled, with greater compassion.

God's plan for life is a mystery, but Myelva's life taught us how to love.

George J. Collins

George J. Collins was ordained a Permanent Deacon in 1978 by Terence Cardinal Cook. After serving eight years in the Archdiocese of New York, he served twenty-five in the Diocese of Palm Beach, Florida. He has been married for sixty-four years and has two daughters and five grandchildren. His website is www.deacongeorgecollins.webs.com.