

Visiting Maggie

By Dorothy Devine

As Maggie's godmother and Nancy's friend, I first felt I wanted to visit Maggie because I did not know what to do to help her. In the beginning I was quite sure she was going to die and I was afraid she would die alone. If I could visit, at least when I was there I could prevent her being alone and hold her hand and tell her that I loved her, praying that she would sense or know that I was there.

Even this early in our journey, Maggie taught me something important. I had finished cancer treatment and still felt very tired ... and sorry for myself. Middle-aged, having done exactly what I wanted for many years and having had many adventures, what happened to Maggie as she just starting out in her young adult life brought me up short and shook me out of my fatigue and self-pity. With this new sense of proportion, I was able to begin to experience what happened to her, and to me as her friend. I had been letting others drive me if any distance was involved and had been staying home the majority of time I was not at work, resting and preferring to be alone. But for Maggie, I could muster the energy to drive many miles to see her, and find the emotional strength to see and understand how very different she now was.

Maggie has now survived for almost five years since her stroke. I have visited her in the original hospital in Worcester, at Spaulding Rehabilitation Center in Boston, in Middleboro Rehabilitation Center, at Morton Hospital in Taunton, at Kindred Hospital in Stoughton, and at Caritas Good Samaritan Hospital in Brockton. Most of the time when she is healthy, she is in Middleboro, about an hour and twenty minutes from my home.

Maggie first was taken to Spaulding for an eight-week program that was their specialty -- waking people from comas. I visited twice, once alone, once with a friend. It was daunting to see the haunted parents of other stricken young people, to hear the story of a young man who played on an escalator and fell, the story of a 17-year-old from India who fell while hanging on to the outside of a train. But Maggie did not do anything reckless or dangerous! She had been studying in her dorm room. These patients, some of whom were held in their beds with nets to keep them from struggling and falling, were horrifying to me. Maggie did not wake up and when the two months were over, she was moved to Middleboro, a nursing home for the brain-injured, where I began to visit, settling into a routine of going once a month on my day off. Occasionally I would be accompanied by one or another friend who had known Maggie a long time as well. But these companions soon fell away, saying it was just too difficult.

What was most difficult to witness was her condition. Her brain stem stroke had made it impossible for her brain to send messages to her body to move. Some clenching of her arms and legs would occur without her willing it, but she was unable to hold her head up when in a wheelchair unless braced. Often I would find her head lolled downward, her face resting in a pool of mucus. The first thing I would do was to get a warm wet towel and clean her and readjust her brace. It also took a while not to be disturbed by the other residents -- young people damaged by car accidents and gunshots, a young mother rendered helpless by a stroke in childbirth. The residents made strange sounds and in many ways resembled the severely developmentally-disabled. But for these residents, the disability had happened in an instant, changing abruptly alert and normal lives. Some had been in the facility for decades.

At Middleboro I stayed about two hours. Since Maggie was not awake (or if she were awake, I could not tell) I found visiting much easier once I developed a routine for our visits. I would greet her and tell her my name. I tell her how I was and how my family was, including the dogs in my report, as Maggie's ambition had been to be a veterinarian. I would rub moisturizer into her hands and feet, taking a long time with every finger and toe. I would brush her hair slowly and gently a hundred strokes. I would take her outside in the courtyard in her wheelchair if the weather was fair, or to a rotunda/lobby where music played if it were cold or stormy. I would sing a song I had learned at a yoga retreat, "Listen, listen, listen to my heart song," I sang, "I will never forsake you, I will never forget you..." I would read some poetry or a couple of short stories. When there was a Christmas craft fair, I took her by a table of homemade soaps and held them for her to smell, "This is patchouli... coconut...strawberry..."

But even with this routine, as soon as I returned to my car I would sit in the parking lot and weep for a long time before I could drive. Was Maggie going to stay alive in this state indefinitely? Why couldn't her parents, my friends, see the sense in removing her feeding tube, calling in Hospice, and letting her go to her rest? Why did they seem to think a life in which she could not move and possibly could not hear or feel was an acceptable life? During these months I "interviewed" the young people I knew. Would they want to live in this state? The answer was a universal, "No." I would cry and cry. When I could finally leave I would find a coffee shop and sit for a long time before driving further.

The day finally came when I received a gift, the gift of acceptance. I returned to my car and sat for while. The sun was shining and I felt a deep calm. There was no reason to struggle so. I was not her mom or her dad. It was not and would never be my decision. That being the case, the only reason for me to visit would be if I could do something positive. It was shortly after this that Maggie had seizures and a series of bouts of pneumonia. She left Middleboro and went to several hospitals, back to Middleboro, back to the hospital. I was surprised that my acceptance was now deeply seated enough that I remained calm, even when I realized that she could feel the pain of her congested lungs and when she bit her lip so hard during a seizure her mouth became disfigured. I would consciously prepare myself early in the morning and make a point of visiting wherever she might be. I would visit a friend or explore a few consignment shops on the way home, not rushing myself back to my usual routine.

Different experiences at the hospitals affected me. At Morton Hospital, Maggie was way down a hallway, far from the nurses' station and there was a male patient wandering around, dressed just in a flimsy "johnny." Suddenly it struck me how terribly vulnerable she was, unable to move and cry out, such a beautiful young woman — she could be the victim of inappropriate sexual attention or assault as long as she lived — by other patients, ambulance drivers, hospital staff, or visitors. At home, nightmares invaded my sleep.

During this period Maggie woke up. My visits were not that different, as I could not always tell, and the routine I had worked out was a structure that served me well. When I visited her in Kindred Hospital, I decided to read her an article by Jerome Groopman that had just been published in *The New Yorker*, about patients in what were called "locked-in states." I slowly and clearly read every word. Then I said, "Maggie, if you are in a locked-in state like this, do you want to live? You are completely handicapped and cannot move, eat, talk, or care for yourself..." Suddenly, Maggie interrupted me with her sobs. I knew she had understood the article and that she understood me. She was very upset, but most importantly, she had heard and understood what I had read. I held her hand and cried some

myself, and said all the comforting words that came to me. I told her how much I loved her, how much her family and boyfriend and friends loved her. Finally, we both calmed down and she slept. Driving home in a snowstorm, watching other cars slide into skids and ditches, what I felt most powerfully was wonder.

In the months and years that followed, Maggie opened her left eye, moved and vocalized more, and began using her eye-gaze to answer "yes" and "no" questions. She read and answered questions written on a whiteboard. She became a test subject at Columbia-Cornell Medical Center where functional MRIs proved her brain was operating normally, if at a slower pace. Sometimes I visited her at Middleboro; sometimes I was able to go with her and her mother or family to see a play or attend an art event or garden party. When I did visit she would indicate if she wanted me to stay longer by communicating agitation when I started to pack up to leave, opening both eyes, moving her torso and arms, making sounds, and then calming down when I agreed to read one more story. I saw more and more willed physical movement and sound. She began to work with special computers able to recognize her gaze and she practices hard at learning to move a cursor. While these developments may sometimes seem slow, the potential for Maggie's quality of life is huge.

I admire her mother, my friend Nancy, who has handled such a difficult situation as creatively as she can. Nancy has advocated for a fitted wheelchair and raised funds for a handicapped van and for treatments like massage, reflexology, and acupuncture. She makes sure Maggie is gotten up and dressed daily. She arranges for speech therapy, for tests at research hospitals, special computer equipment, and participation in cutting edge developments in neurological care. She had enhanced experiences of all the residents by organizing musical events and meditation sessions with a monk from the Zen Center. Nancy does become discouraged and sad and, when she seems particularly down, I have dinner with her and listen.

I will keep visiting Maggie, I know, for many years. She will continue to teach me to communicate with her and to understand what she wants. She has taught me that I can love her without anguish despite the huge change in her. She has taught me extremely valuable lessons: a sense of proportion, as well as acceptance, patience, admiration, and now, wonder. Only time will tell what the other lessons will be.