

## Violets Do Well in Sunlight and In Shade

It was a Thursday in early July. The head of nursing had specifically asked that I see a patient who had been admitted a few weeks before. She was demanding to be allowed to go home, which was not an uncommon request in most nursing homes. But this patient seemed intent upon leaving. When I arrived on the unit the charge nurse explained that the patient had been causing quite a stir with her demands. She had been difficult since the day of her admission. She had refused to cooperate with the floor "routine". The nurse explained that I would have been called earlier, but they realized I was unavailable because of my father's recent death. Indeed, this was my first day back since his death. He had been a patient at another nursing home in the same city.

As I flipped through the chart I remembered how difficult being there had been for him. My mother and I and my wife had provided care for him as long as we could, but when it had reached the point where two people were required to dress him, it was clear that he could not remain at home alone with my mother. Although he received good medical care at the Center and my mother visited him each day, he declined quickly and died within a year after being admitted. I could certainly sympathize with any patient wanting to stay in their own home as long as possible. The question that I was asked to decide that morning was whether or not the patient was competent to make such a decision. A few months before, Violet had been diagnosed with Lou Gehrig's' disease. ALS is a generative neuromuscular disease that is terminal, with death usually coming within a year and a half to two years after diagnosis. I knew the course of this disease quite well since my office manager had died of ALS only six months before. "What a day this is shaping up to be," I thought. "I get to deal with Leo's and my Dad's death the first morning I'm back with the first patient I see".

Needless to say, as I walked to Violet's room I had a number of things on my mind. When I arrived at her door I found a frail looking women in her late seventies who immediately smiled at me and asked if I was the doctor that was going to let her go home. It would be an understatement to say Violet did most of the talking that morning. She explained to me that she had to go home, that she really had no choice. She lived with her adult son, who was retarded, whom she had cared for all of his life. She also explained that she had a garden and it was the middle of summer and there was much to be done in her garden and that there was no one else to tend it. She was willing to accept home care services, which had not been attempted. She seemed very clear about the grim prognosis for her disorder and that most likely she would be seeing me again soon. But for the time being she wanted to be at home with her son and her garden. After a few more questions I determined that Violet was indeed competent in the eyes of the state to make such a decision and assisted her in calling a cab since she explained to me that she had already packed her bags the night before and was ready to go.

It was the late fall before I saw Violet again. She had returned to the Center, again under protest, after she had fallen a number of times and the home nursing service had decided that they could not continue to provide care for her. She was also losing the ability to speak. She could still walk with some assistance although she was now in a wheelchair most of the time. When I saw her that morning she was mainly concerned about her son and his care. Her younger son had said that he would be willing to take over some of the responsibilities for supervising his older brother. Violet seemed worried about this, but accepted that her younger son would have to take on this responsibility. I agreed to attempt to

find other services that might be of assistance to both of her sons and suggested that perhaps her older son would need to eventually move into some type of group home or supervised living situation.

Violet had brought only a few things to the nursing facility. Mainly, her possessions consisted of a few potted plants that she had put by the window on admission. Over the months that followed I saw Violet frequently. Many of these consultations were at the request of the nursing staff who remained quite concerned that Violet would not comply with the "policies" of the facility. She was forever getting up and falling. She explained that she simply did not have the time to wait for the nursing staff to assist her when she wanted to do something, such as tend to her plants. Violet was also having increasing difficulty in communicating and by early winter had reached the point where she could not speak. Her arms and legs were also getting weaker and I worried about the time that she might face when she could not communicate at all. When Leo died he had reached the point where his only method of communication was moving his eyes up or down to indicate yes or no.

Her family visited occasionally. Her older son had adjusted now to a different routine. Community service agencies had gotten involved in working with him and the family. Violet continued to talk of her garden. She made a few visits home. But as the muscles in her throat began to deteriorate, she was having more difficulty eating and swallowing and had more frequent episodes of choking. The illness was progressing.

Violet frequently wrote me notes about her family and her children and about her husband who had died many years before. She continued to complain about the Center "routine" and occasionally made "jokes" (which the nurses sometimes took seriously) about jumping out the window and running away from the center. Through it all Violet projected a sense of quiet confidence and control. She did not see herself as helpless, although others might have thought of her as such.

By mid-summer I had made the decision to leave the Center and to develop a practice in another state. This was a difficult decision for me and I hesitated to tell Violet that I would be leaving. When I finally did and suggested that I had recruited another psychologist who could "take my place" she laughed and told me that she didn't think she would be needing to see the new person. Since my departure was only a few weeks away I disagreed, explaining to her that the prognosis for her illness still suggested that she had many months maybe even years left to live if she chose, since in many cases the illness "plateaued" and the progression was arrested for a period of time.

But true to her word, Violet died a week before my departure. I visited her a few days before her death. She asked me to roll her chair outside and we sat in the warm sun of an early September afternoon. We talked about her family and her death and Violet once again told me the time was very close. A few days later I was called by the nursing staff. Violet was losing consciousness. She was having more difficulty breathing and the physician, because of her restlessness had decided to sedate her. My last memory of her is standing by her bed holding her hand as she slipped into a very deep sleep, from which she would not return. Violet was one of those patients who touched your head and your heart. She had seemed from the very beginning intent upon teaching us a lesson about the importance of maintaining control over our life to the very end. It was this that allowed Violet to do well in the sunlight and in the shade.