Promise, unfulfilled potential in elderly care

By RUTH MORGAN

Few people have the opportunity to experience seeing something dramatically change for the better. I have had that opportunity over the last 19 years, watching the changes in the quality of care provided by nursing homes as the Barren River District Long-Term Care Ombudsman.

My first nursing home experience was when I was a teen. I decided to volunteer one summer at a local nursing home. I will never forget my first experience at a nursing facility. The smell of urine permeated the air as I entered and it almost made me sick. I was horrified to see several people tied to chairs. They seemed groggy and made strange moaning sounds. The halls were dark and the sounds disturbing.

The young lady who greeted me was cheerful. She seemed oblivious to all the sights and sounds that surrounded her. She introduced me to an elderly gentleman named Bill. She told Bill that I would be coming to visit him every week over the summer. Bill was wearing a dirty shirt, pants that were partially unzipped and too big for him. He had on socks with no shoes and one toe stuck out. He walked with a stagger, drooled out of the side of his mouth and grunted as he tried to communicate.

I was handed a piece of cardboard on which someone had written the alphabet in crayon and told that Bill could spell by pointing to the letters. The letter board had obviously been made a long time ago and was stained with what looked like dried food. The young lady smiled as she handed me the board and left the room. I was alone with Bill. I had no orientation and no idea what I was supposed to do. At 16 I found the whole situation terrifying.

Throughout the summer I visited Bill several times, although not weekly as he expected. I always called before I came and Bill was always waiting for me. He never looked any cleaner and often smelled of urine. I held back the gags and pretended not to notice. Normally, when I arrived, I got two Cokes from the vending machine, one for each of us. Bill said the only sodas he got were the ones I brought him. We would sit in the lobby or out in the yard and talk using the letter board.

Talking with Bill was a painfully slow and our discussions were rather shallow. We talked about the weather and what Bill had eaten. He said the food was awful. Sometimes, I would bring a checkerboard and we would play a game. Bill always won. It seemed to me that Bill never did anything in between my visits. I will admit that while I felt bad for Bill, I was glad when the
summer was over and my obligation done.

In my 20s, I took a job at a different nursing home. It seemed to be a much better facility than the one Bill lived in. I was in charge of the activities and social services for a 60-bed facility. I was educated as a social worker, and had no training at all in recreation. I was responsible for scheduling activities, mostly played bingo, talking with the residents and delivering the mail. Occasionally I took residents out to sit on the porch but that was pretty much it.

In 1988, after graduating from Western Kentucky University with a degree in social work, I became the Barren River Long-Term Care Ombudsman. I soon became aware that something special had just happened. Nursing home ombudsmen and other advocates were excited about a new federal law that had passed. According to them it held great promise for improving the quality of life and care in nursing homes. We ombudsmen were going to be on the forefront of a wind of reform educating the public and advocating for full implementation.

That was 1988.

So, what was the impact of this new law? Did it really make a difference? The truth is that the law has resulted in unbelievable and dramatic improvements in the quality of life and care experienced by residents of the nation's nursing homes. But the promise of the reform law is far from being reached. This 20-year juncture is both a time to celebrate and a time to contemplate how we will move forward.

In 1988, 40 percent of all nursing home residents were physically or chemically restrained, often both. Declining condition, dehydration and weight loss were expected. Nursing homes were depressing places to be avoided at all cost.

Today, restraints are used much less often and closely monitored. It is accepted by everyone that residents have rights which must be respected. Facilities are cleaner, more homelike. Nursing home staff work in teams to develop comprehensive care plans that meet individual needs. The enforcement process has changed and become more open. Regulators have stopped looking at what nursing homes are supposed to be doing and started looking at resident outcomes. And those outcomes have improved.

But the outcomes are still far short of what the law promised. Too often consumers still find that poor care is tolerated and insufficient staffing the norm. Some facilities yo-yo in and out of regulatory compliance. Residents still report violations of rights and tolerate indignities. We have learned that we must address the culture of care as well as the regulatory aspect of care if the goal is to be achieved.

I can't help wonder what Bill would think of all this.

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