

My name is Kathy Bradley. My mother, Carol Hay, was a lifelong activist for social justice, advocating for those whose voices were muffled, ignored, or silenced by the powerlessness of their marginalized station in our society. Whether speaking out for our children's education, for civil rights, or for protection of our planet and its resources, my mother was strong. Whatever the obstacles confronting her, she would not be silenced. She also had a joyous love of life that never quit. I learned a lot from my mother.

Then, at the age of 72, my mother was diagnosed with dementia. Slowly advancing at first, she remained able to live in her home with my father until the age of 76, when she experienced a sudden and dramatic loss of cognitive and functional abilities. She had to go into a nursing home. The first thing this cruel disease robbed from her was the ability to speak. This strong, outspoken social activist, who had used her voice on behalf of so many, all her life, was suddenly silenced.

In this so-called "Cadillac facility," affiliated with a prominent denomination of the Christian church, boasting a "caring staff" and a "lofty mission", my mother's treatment did not meet even her basic human needs. She lost her ability to perform basic self-care activities such as bathing and dressing. A modest and fiercely independent woman, she was put in the position of having strangers expose and touch her whole body, and in a manner she considered "not even decent." Yes, those are her words – she managed to get those words across to me in her desperation to be treated with respect. Because she wandered, she was tied in a wheelchair "to prevent falls." Her requests to get out of her chair were ignored.

Activities in this facility were nonexistent. One day, in an effort to offer my mother some semblance of quality in her daily routine, I noticed an activity on the schedule that would have piqued her interest: baking brownies. Mama had been a gourmet cook in her day, and we sometimes had fresh-baked brownies in our house when I was growing up. The act of combining the ingredients and putting them in the oven, the enticing smell of the brownies baking, and the opportunity to eat the resulting delicious treat – all would be familiar to her and bring back positive feelings, as in years past. "Perfect!" – I thought. Perfect activity for people with dementia, and especially for someone with Mama's life experiences.

As Mama and I approached the kitchenette about 5 minutes before the appointed time, no smell of brownie batter greeted us, no sound of residents or staff talking, no clinking of bowls and baking dishes. We rounded the corner into the kitchenette. There sat two staff at the kitchen table. A dish of already-baked brownies was stored away on top of the refrigerator. Staff looked at us incredulously, as if they had never seen a resident attend an activity before. When I asked about the activity, they quizzically replied that they – the two of them – had already baked the brownies. They didn't even have a clue that what they had done had destroyed the entire point of the activity.

That was life in a private-pay, "Cadillac," "Christian-based" facility with "caring staff" and a "lofty mission."

There was no expectation that the staff would implement even basic activities, recognize individual preferences or personality traits of the residents, or in any way alter their habits in consideration of those they were there to serve. Not even something as simple as helping someone who wanted to get up and walk around. And there were no consequence if they didn't. So they didn't. You see, human nature is to do what is most comfortable. The culture in that and most nursing homes, left to their own devices, is what is most comfortable for the staff.

Then came Medicare. Having been a provider of long-term care for 33 years, a Licensed Nursing Home Administrator for 23 of those years, I knew what that meant. There would be an expectation of at least minimum standards of quality of life, consideration of each resident as an individual person, and a mechanism for making sure those standards were met. To say I was relieved is an understatement. I had made many attempts to work with the staff of the facility, offering suggestions and ideas based on my

experience with federal funding and regulations, to no avail. But having the federal regulations to support my efforts would give the staff incentive to improve.

It was not an easy road. My mother ended up hospitalized, and returned to the facility under Medicare funding. She received physical and occupational therapy and speech therapy. The nursing home was about to undergo their first full survey, having been recently accepted into the Medicare program. But they did not yet have a solid understanding of what that meant. After many failed attempts to help and support the nursing home to come into compliance before their survey, I made the decision to take the information I had amassed to our state survey agency. They used my concerns to inform their survey, and found that the issues were not just my mother's issues, but were pervasive throughout the organization. Only after the survey team cited the facility for the deficiencies that I had tried to warn them about did things begin to change. And, although the struggle never ceased, the Medicare program and its regulations became the foundation for my mother to experience quality in her daily life; to receive therapies she needed to keep her moving and eating and making the most use of whatever abilities she had left; and to be treated with dignity and respect as a person – in the way staff interacted with her, in the way she spent her time, in the foods she was served – all the things the rest of us take for granted.

Medicare funding and the regulations that come with it made the difference between my mother's being treated like a list of tasks to be completed before the end of a shift, and her experiencing whatever life she had remaining in ways that were important to her; between being treated like a faceless form in a sea of sedated bodies in wheelchairs, and being respected for who she was and who she had been and what she had accomplished in her life. And, thanks to the way the regulations are designed, even after Medicare no longer paid for her nursing home care, the quality of care and access to services were required to be the same regardless of pay source. So she continued to reap the benefits of that quality of care and treatment until the end of her days.

Now, if you think you can buy this quality of life for your own mother with your own money, and if you think taxpayer money and the regulations that come attached to public funds are “unnecessary burdens,” you are mistaken. “Clean (maybe), dry (maybe), dressed (maybe), and fed (maybe)” is what your money will buy. Because that's what is convenient. I have seen it, from the inside out. I worked in the field for 33 years. I know. I know the show that is orchestrated for visiting families, and I know what happens on third shift on the weekends. “The goodness of people's hearts” doesn't make for your mother's being treated the way she should be. Private money doesn't buy good care and quality of life. (By the way, my parents and our extended family have been significant benefactors to my mother's facility and its parent organization for generations. So I also know for a fact just what influence private money buys in nursing homes. It may make you feel important when you visit; but it doesn't buy good care.) Public funds and the regulations that require a standard of care and services are your only defense against mistreatment of your mother. And they are what gave my mother 5 years of the care and support she needed to have some quality of life in her last years.

My mother, the activist, was able to continue to be her own advocate through her children. We carried on her advocacy for a group without a voice even as she became a member of such a group – nursing home residents who cannot speak for themselves. We carried her voice to those with the authority to make change happen for her and others in her nursing home. We carried her voice to establish a nonprofit organization, Our Mother's Voice, that informs and empowers other families to advocate for their loved ones in nursing homes who cannot speak for themselves. We continue to carry her voice, bringing it to you today.

Medicare, and its requirements for participation, are a lifeline for vulnerable people who cannot speak for themselves. For my mother. For YOUR mother. Perhaps for your wife or husband, or even for your child. Maybe one day even for yourself.