

NONPROFIT SPOTLIGHT: OUR MOTHER'S VOICE

Kathy Bradley turned her mother's story into an organization that helps us help others

In 2009, at age 76, my bright, accomplished, exuberant and loving mother suddenly declined into severe dementia. She could no longer speak or execute simple daily living or self-care tasks. This strong, independent woman resisted my father's help and wouldn't cooperate with in-home care. She needed the structure and assistance of a nursing home. My mother, a lifelong activist for social justice for groups in our society without a voice, became a *member* of a group without a voice: nursing home residents who cannot speak out when something isn't right.

My first career consisted of providing long-term care for people with developmental disabilities, so I was quite familiar with the long-term care service arena and regulations. And I knew how to organize these complex services to meet people's needs. I became my mother's voice: I "listened" to what her behaviors were communicating and I spoke up on her behalf to advocate for what she needed to have what she called "decent" treatment.

Unfortunately, the staff were trained to conform all residents to the facility's schedule, routine and way of doing things without regard for each resident's personhood. My mother wanted to do what SHE enjoyed, what was meaningful to *her* — only she couldn't on her own. Staff labeled her combative, resistant to care, noncompliant and agitated, and tried to medicate her into compliance. I refused consent to these medications and pushed for staff to learn my mother's language: behaviors that were telling them what she needed and what wasn't right.

All seven levels of organizational hierarchy rejected my pleas. Our family utilized our state's regulatory agency to change the facility's practices. Surveyors found that the practices were systemic and cited deficiencies. Change began to happen for my mother and all residents. The process was long; the results were amazing. My mother went from suffering from dehydration and urinary tract infections every six weeks to enjoying two years of good health. She received therapies that kept her as strong as possible and assist with daily personal activities, and enabling her to chew and swallow whole foods, not just ground-up globs. All the residents benefited from these changes.

My sister asked, "What do families do without someone who knows how to make the system listen?" Our Mother's Voice was born. Established in 2010, we provide no-cost information and resources to empower advocacy for those in long-term care, in any setting. Our website includes essential, practical information about what quality care looks like, how to recognize quality of life in daily routines, resident rights (and how families can exercise these rights for their loved ones), step-by-step tips for empowered advocacy, and scores of additional well-organized resources. We conduct online and in-person presentations on many topics. We provide individualized information and resources for those needing more specific information for their situation. We do the research because we know what to look for and where.

For more information visit ourmothersvoice.org or email us at contact@ourmothersvoice.org