
Second acts



>> "My sons thought I was going through a midlife crisis when I told them my plans," says Berry, shown near a care facility she created.

What she couldn't do for her mother

Dementia turned her mom's last years into a living hell. So Judy Berry created a program that is saving others from a similar fate

BY JULIE HALPERT



In 1989, Judy Berry got what she describes as "the call that changed my life." Her mother, Evelyn Holly, who suffered from early-stage dementia, had accidentally overdosed on her medication and needed to be hospitalized. At the time, Holly was living in an apartment in an assisted-living facility. Now Berry was forced to move her into the facility's dementia-care unit. "My mother had made me promise never to do this," says Berry. "But I had no choice."

Accustomed to going on five-mile walks nearly every day, Holly was now permitted only strolls down the hall.

In the first week, however, she wandered onto other floors, and it took the staff four hours to find her. The facility soon judged her rambles a liability, so they moved her into a locked unit and, says Berry, "told her she'd live there and could never go out. She'd periodically go berserk, hitting and kicking. They had to hold her down to give her injections. She was like a caged animal."

At one point, desperate to relieve her mother's suffering, Berry moved her into a mobile home set up on land Berry owned near her house

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>> Two Lakeview Ranch caregivers guide one of the residents as he walks with the help of a support device.

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in St. Cloud, Minnesota. Even though Berry had space to spare, her mother preferred to be in her own home, with her own furnishings. Berry hired two carefully chosen, experienced caregivers to look after her, but even they were unable to head off the aggressive episodes. Within three months Holly was back in a nursing home. “I learned a huge lesson, which was how much I didn’t know about dementia,” says Berry. “When I visited my mother, her eyes would light up, and then the tears would start running and she would just keep saying, ‘Help me! Help me!’” Until her death in 1996, Holly’s violent behavior got her kicked out of 12 facilities and repeatedly hospitalized. She spent the last two years of her life heavily medicated and confined to a padded reclining chair.

➤ **Throughout her** mother’s ordeal, Berry threw herself into researching dementia programs. She imagined that someday she might open her own facility, even if her mom was no longer alive. By day, Berry worked as a regional sales manager for a meat company, selling barbecued ribs to grocery stores in multiple states. In her spare time, she’d phone facilities around the country

and schedule visits between sales calls so she could interview the staff about the approaches that worked best. She combed through the medical literature on caring for dementia and Alzheimer’s patients. She learned that the only way to prevent aggressive or violent behavior is to recognize the emotional need behind the behavior and address it immediately. Gradually, her vision of a new kind of facility coalesced. “Patients lose the ability to communicate their needs,” she says. “So caregivers need to learn to tap into the emotion behind the words and read the nonverbal signals.”

In her thirties, Berry had owned a dairy farm with her then husband. She joined the meat company when she was 45, and although she had no savings, she did earn bonuses every year. She used that money to buy pieces of farmland, believing that a tranquil, pastoral environment with enough space to accommodate an animal-therapy program would be best for the future residents. By 1995 she had 15 acres, but raising the funds to build proved nearly impossible. For four years, bank after bank denied her a loan. She kept trying. One day she walked into a bank to give her pitch and was assigned to meet with a vice president. During their meeting, he revealed that his mother had been hospitalized for violent behavior three times in the previous six months. “He was going through the same pain and frustration I’d experienced with my mother,” says Berry. “He decided he would help me apply for a Small Business Administration loan that would then partially guarantee the bank loan. There was tons of paperwork, and on closing day, wow, what a case of the jitters I had.”

Finally, in 1999, at age 55, Berry achieved her dream of building the kind of home she’d hoped to find for her mother. Nestled on a rural swath of land in Dassel, Minnesota, Lakeview Ranch (lakeviewranch.com) is a haven for hard-to-place patients with severe forms of dementia. Within eight months, all 14 beds were filled, and three years later, with a waiting list in hand, Berry opened a second facility nearby.

➤ **Today Lakeview** Ranch’s two facilities are home to 30 patients, and Berry is recognized as a leader in the dementia and gerontological fields. She speaks at conferences around the country and provides staff training and consulting services for other facilities. In 2010 the prestigious Robert Wood Johnson Foundation honored her with its Community Health Leaders Award.

Although many of Berry’s patients had been frequently hospitalized for behavior-related issues before arriving at Lakeview, the facilities have had only four such hospitalizations, all in the first years, and they don’t use any medication to control patients’ behavior. A 3-to-1 ratio of patients to caregiver means the

Running the numbers

➤ **\$243**

Daily cost to house one resident

⊕ **\$2.4 million**

Annual operating expenses

⊖ **\$2.2 million**

Annual revenue from operations

⊖ **\$160,000**

Monthly staffing costs

➤ **\$60,000**

Berry’s annual salary



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staff can get to know each patient and anticipate his or her needs, though it also means Berry's staffing and training costs are higher than at most other dementia-care facilities, where the daytime ratio is about 7- or 10-to-1.

An animal therapist is on site every day. "Animals have a way of calming people," says Berry. "We use them for defusing anxiety, getting residents to do treatments they are resisting. Animals bring joy into their lives." Each facility also has a music therapist twice a week, six activity specialists and two registered nurses. Licensing regulations don't require a full-time, on-site nurse, but nurses can catch physical problems like urinary tract infections early. Having the nurses and a favorable patient-to-staff ratio means the facility can "stop anxiety from turning into a full-blown event," she says.

Berry recalls one resident who paced the halls at night. Most facilities would have given her a sleeping pill and ushered her back to bed. But Lakeview staff knew from the history her family had provided that the resident was previously a night nurse. The staff gave her two dolls to rock at night, "and it made her happy until the day she died," Berry says. On another occasion, a resident began tapping his chair loudly. A caregiver immediately went over to him, saw that he was drooling, wiped his mouth and asked, "Are you all right?"—and the resident promptly stopped. The tapping was his signal that he needed attention, that something was making him uncomfortable, explains Berry: "This is the kind of gesture that, if not addressed right away, can turn into more aggressive behavior."

No matter how severe a toll dementia takes, Berry believes each person retains his or her essence and humanity until the very end. She recalls visiting a 94-year-old Alzheimer's patient who was near death. The man's twin sister was sitting by his bed. "He hasn't been aware for two years," the sister said. Berry started rubbing the man's hands, which had gone cold, leaned close to him and said, "Reuben, I want to tell

you how great it's been to have you here and that it's OK to go." He fluttered his eyelids, squeezed her hand and said, "Thanks for caring." His sister wept and told him how much she loved him. He died three hours later. Afterward, the sister told Berry, "You gave me the biggest gift. I would never have believed he was still in there."

» **One of Berry's goals** is to make Lakeview Ranch affordable for low-income people. Most of her patients' families are unable to pay the full annual fee of \$88,695. "I know how it feels to be turned away because of lack of funds," says Berry. Unfortunately, Medicaid covers only about a third of the cost of a resident's care at Lakeview because the program reimburses facilities primarily for the cost of hospitalizations, emergency room visits and drugs. In effect, Lakeview's practice of keeping residents healthy and eliminating violent behavior means it has sacrificed substantial Medicaid funding. Berry's solution: She started a 501(c)(3) charity, the Dementia Care Foundation. From 2001 to 2014, when Lakeview began operating as a non-profit, the foundation raised more than \$1.5 million in donations to supplement the gap between Medicaid and the cost of the program.

She is now collaborating with Minnesota's health and human services departments to show how proactive dementia management can significantly cut costs. She's optimistic that health care reform, with its focus on tying reimbursement to positive outcomes, will provide incentives for more programs like hers. She started a new company, Dementia Specialist Consulting, to spread the knowledge she's gained. Berry, who remarried in 2006, is undeterred by the challenges ahead. "I'm the happiest I've ever been," she says. "I want to be part of the change that makes it possible for all elderly to maintain their basic human rights." *

JULIE HALPERT's previous Second Acts profiles featured a wine-bar proprietor and a basketball-team owner.