

“It Broke My Heart That I Couldn’t Protect My Mom”

Martha Deaver was kept from seeing her frail, elderly mother for almost three months by an Arkansas nursing home

Could you be banned from a nursing home and prevented from seeing your ailing parent just because you complained about poor care? Experts claim reports of such cases are on the rise

The scene that met Martha Deaver when she arrived at St. Andrews Place Nursing Home was nightmarish. Her 80-year-old mother, Helen Steger, was in the grip of a violent seizure, her body shaking, her eyes fixed and bulging. This shouldn't be happening, Deaver knew—her mother had been on a drug that successfully prevented such seizures since she'd had a stroke three years earlier. But only weeks after Steger moved into the Conway, Arkansas, home she mysteriously suffered a new attack. “My mother spent her entire life caring for others,” recalls Deaver, then a

47-year-old homemaker. “Now it was my turn to care for her. I needed to find out why the drug wasn't working.”

After talking to a staffer, Deaver says, she felt she had grounds to believe that her mother wasn't getting all of her antiseizure medication. She took her concerns to the nursing home administrator, but she felt that he downplayed the problem. So she filed a complaint **CONTINUED**

By
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PHOTOGRAPH: DANA FIREMAN; HAIR AND MAKEUP: ANGELA E. ALEXANDER

with the Arkansas Office of Long Term Care. "My mother's seizures were horrifying—I had to make sure the nursing home acted responsibly," Deaver says. (St. Andrews Place's administrator and attorneys have declined comment on the case.)

When state investigators arrived, they found even more problems. Not only did they discover that Steger had not been given her full quota of prescribed doses, but the state regulatory office found that during the month it visited St. Andrews "there was no system of documentation in place to ensure that residents were receiving the correct and accurate medications." The state fined the facility several thousand dollars for dangerous deficiencies in care. Deaver felt heartened that the system had worked and satisfied that she had done right by her mother.

But the matter didn't end there. On October 23, 2000, only a few days after St. Andrews was fined, the home successfully sought a temporary restraining order against Deaver, her husband, Ronny, and their grown son, Bryan, banning them from the premises.

"I was shocked," Deaver remembers, "completely blindsided. They were telling me I couldn't even see my mother!" After consulting a lawyer, who told the family that courts issued temporary restraining orders on the basis of the sworn testimony of the plaintiff and that they would have to appear in court to contest the charges and dissolve the order, Deaver's first thought was simply to move her mother to a different nursing home. According to Deaver, her father placed numerous calls but even when the availability of beds was confirmed, before final arrangements could be made the nursing homes that had promised space would withdraw their invitations. "It was quite clear that we had been black-listed because I complained," Deaver says.

Under Arkansas state law, families have the right to respond to such restraining orders within 10 days. Deaver did so but her hearing date wasn't until some five months later, on March 14, 2001. As she waited, Deaver grew increasingly desperate. Cut off from her mother—Steger was all but incapable of speech, making even telephone conversations impossible—she had no firsthand way to know whether the medication issues had been remedied, but says she heard that her mother's health was deteriorating. Then her worst fears came to pass. On January 15 Steger went into respiratory failure and was taken to the emergency room. At a hospital, on life support most of the time, she lingered for nearly two months. Since the restraining order didn't affect the hospital, Deaver and her family were at last able to see Steger, but she died on March 12, just two days before the family got their court hearing.

Although Deaver prevailed and the restraining order was lifted, it was, to say the least, a hollow victory. Finally allowed to enter the nursing home, Deaver returned one last sad time to collect her mother's belongings. "It was torture for me," she says quietly, "not to be able to see my mom in the last months of her life."

Today St. Andrews Place continues to operate. After her mother's death Deaver filed a civil lawsuit against the nursing home alleging, among other things, medical malpractice, negligence and violations of resident rights. The case will be heard later this year, when Deaver hopes to bring closure to her five years of grief. "This case is about a nursing home retaliating against someone for filing legitimate complaints," says David Couch, Deaver's Little Rock attorney. "Martha was just trying to advocate for her mother, as every child should."

WHAT FAMILIES FEAR

Placing a loved one in a nursing home is never an easy decision; concerns about quality of care only add to a family's distress. And those fears are not unfounded: From 2001 to 2005 nursing home safety and health violations rose 26.8 percent. Last year state health inspectors cited a full 91.7 percent of America's 16,400 nursing homes for at least one deficiency—including the neglect or mistreatment of patients—and about 12 percent of nursing homes were cited for more than one deficiency that caused actual harm. "Our health-care system is failing the most vulnerable members of our society," says Representative Henry Waxman, a Democrat from California and a member of the House Committee on Government Reform, one of the committees that monitor the nursing home industry, who is making nursing home reform his signature issue. "And the quality-of-care problems in nursing homes keep getting worse."

Given this reality, relatives often play important roles as advocates for their institutionalized loved ones. But experts claim that they are hearing an increasing number of stories like Deaver's, where family members who complain about nursing home inadequacies face retaliation, sometimes to the point of being banned from the premises. Although experts are unaware of any agency that compiles statistics on these **CONTINUED**

reprisals, advocates for the nation's 1.6 million nursing home residents say that the number is rising. "The trend is to get rid of troublesome families because they're too demanding," says Patricia McGinnis, executive director of the California Advocates for Nursing Home Reform, a San Francisco-based advocacy organization. "Nursing homes have to spend more time with complainers and fear litigation if they can't satisfy them. We're seeing more retaliation than ever before against those who stand up for their rights." And with the country's 85-and-over population set to almost double by 2030, there will likely be a parallel increase in nursing home complaints.

Federal law has long granted nursing home residents the right to see their family members 24 hours a day unless the visitors are deemed a danger to residents or staff. But recent cases suggest that some nursing homes are now labeling merely outspoken people as "dangerous" as a way to get courts to issue restraining orders against them. Family members who draw attention to poor care may even find themselves facing arrest. "If a person is on private property, and the custodian of that property contends that the person is committing some sort of breach of peace or a disturbance, then the police are going to enforce the property custodian's right," says Jim Pasco, Jr., executive director of the National Fraternal Order of Police.

Nursing homes rarely ban a resident's relative from their facilities and then only when the person presents a real danger, maintains Larry Minnix, president and CEO of the American Association of Homes and Services for the Aging, a Washington, D.C.-based group of nonprofit nursing homes, assisted-living residences and other service providers. "We see a lot of frazzled family members who show up loaded for bear," he says, noting that busy families often show little patience when dealing with their parents' caregivers. "We are in the peace-of-mind business," Minnix says, adding that retaliation against relatives occurs only when there's inexperienced staff, little supervision and poor communication between administrators and families. "If there's good communication, families will be forgiving if we make a mistake."

Indeed, good facilities routinely address care and quality-of-life issues without state investigators intervening. Judy Garber learned



Brenda Durant, here in front of the Granbury, Texas, courthouse, feels that a state investigation into her mother's nursing home was deeply flawed

this firsthand last November when her 84-year-old father, Arthur Rosenberg, a resident of the Hebrew Home at Riverdale, New York, became despondent over his wife's death. Garber was concerned and met with her father's social worker and nurse about his depression. Within hours the home's staff had mapped out a plan to help him out of his despondency, including increased visits from his social worker and more invitations from nurse's aides to various activities. This strategy got him reengaged and active in everyday life again.

"We don't get defensive about complaints," says Daniel Reingold, president and CEO of the Hebrew Home. "We use them to design programs that better serve family concerns." Reingold, a 15-year veteran of the facility, recognizes that satisfying families has become an increasing challenge as demanding baby boomers have become their parents' caretakers. "Families used to be more accepting of whatever services we provided," he says. "Today they come in with a mother who has Alzheimer's, a feeding tube and a broken hip and get upset if we can't get her dancing the polka. But our goal is to do our best." CONTINUED

HAIR AND MAKEUP: LANA ADAMS FOR KIM DAWSON AGENCY

A SHORTAGE OF CARE

Nursing homes are businesses, and financial pressures can result in some homes being ill equipped to be responsive. All nursing homes, whether large chains or independent facilities, for profit or not, face rising health-care costs. Some 65 percent of residents pay through Medicaid, which provides around half of the annual cost of care. According to a recent survey, a private room in a nursing home costs an average of \$70,912 a year. Although many homes nonetheless manage to turn a profit, the corporate focus on the bottom line can result in inferior care. "The problem is that facilities don't get enough money from their owners to promote quality care," says Janet Wells, policy director of the National Citizens' Coalition for Nursing Home Reform (NCCNHR), an advocacy group in Washington, D.C. "And in the face of complaints, administrators become defensive and overreact."

A corollary of insufficient funding is inadequate staffing. A recent federal study found that to reach optimal staffing levels, nursing homes would have to hire between 77,000 and 137,000 additional registered nurses, between 22,000 and 27,000 more licensed practical nurses and between 181,000 and 310,000 more nurse's aides. Facilities hire a greater number of licensed vocational nurses than more rigorously trained registered nurses, who cost more. And while residences must retain physicians, those doctors are required by law to see each patient only once every 30 days for the first 90 days after admission and once every 60 days thereafter.

Consequently, aides provide most direct care to nursing home residents. The average nursing home employs one aide for every 12 patients, according to nursing home researcher Charlene Harrington, Ph.D., a professor of sociology and nursing at the University of California, San Francisco. But she maintains that the optimal staff level is one aide for every five residents. "More than nine out of 10 nursing homes are understaffed," says Dr. Harrington. "That means residents suffer." Understaffing can result in residents being allowed to soil themselves because they're not taken to the bathroom regularly, to become dehydrated and malnourished and to suffer painful ulcers because they're not regularly moved. Genevieve Gipson, director of the National Network of Career Nursing Assistants, a Norton, Ohio-based nonprofit group, points out that even the best-intentioned aides cannot overcome the difficulties of understaffing. "Aides caring for eight patients don't have time to go to the bathroom themselves," she says. Working in these conditions for around \$8 an hour, aides unsurprisingly don't last long. Annual turnover rates average 71 percent but can be more than 100 percent (since a position may need to be filled several times in the course of a year).

Not only are nurse's aides overworked and underpaid, they are also poorly trained. Federal law requires that aides get only a minimum of 75 hours of training for certification. "It can take

more time to become a manicurist," says Catherine Hawes, Ph.D., a professor of health policy and management at Texas A&M Health Science Center, in College Station. "The woman doing your nails might very well have more training than the one taking care of your mother."

Given this, residents' families often have cause for complaint. Forty-four percent of nursing home residents reported having been physically abused (punched, kicked or choked) in a 2000 study of 80 patients in 23 Atlanta homes, and 48 percent said they had been treated roughly (flung into bed, shoved or jerked). Some 95 percent claimed to have experienced or seen neglect. Even in egregious cases, the possibility of reprisals often prevented residents and family members from complaining. About half of the Atlanta residents reported that they feared retaliation by the staff. "Residents feel a tremendous dependence on the nurses," says Dr. Hawes. "It's natural to think that if you get nurses angry they won't take good care of you."

WHEN THE SYSTEM FAILS

But families won't necessarily fare much better if they take their complaints to an authority outside the residence, either. Typically, they are directed to local ombudsmen who are available in every state to deal with long-term care and nursing home issues. The number of disputes handled by ombudsmen rose 33 percent from 1999 to 2004, to 287,824. But the involvement of ombudsmen doesn't guarantee that complaints will be addressed to the family's satisfaction. There are 580 local ombudsman programs across the country, but they use almost eight times as many volunteer staffers as professional employees. And none has power to penalize a home for deficiencies, only to negotiate between a facility and the resident's family.

After trying the ombudsman route, family members who feel their problems weren't resolved can turn to their state's health department, which does have **CONTINUED**

THE RIGHT WAY TO COMPLAIN

When your loved one is suffering, your first reaction is likely to be outrage. While you may want to scream at a careless aide, pause to consider what's ultimately best for your family member. Controlling your temper may be hard but keeping a civil demeanor will help get your complaints resolved more quickly. Here, the protocol to follow:

1. Talk to the staff responsible for your loved one's care. Don't accuse or attack them, but let them know what the problem is clearly, calmly and respectfully. Intemperate words not only will antagonize the staff but can also be used to "prove" you're a danger. If a worker cites reasons for the lapse, listen to her, make sure you understand and ask how you can work together to prevent the situation from recurring. At

home, keep a log of such conversations. If the situation is resolved successfully, thank the staff members involved.

2. If the problem isn't corrected in a timely way, complain in writing to your nursing home administrator. Again, be civil. Describe the issue and your efforts to resolve it clearly, without berating or threatening the staff. Keep copies of your complaints, all responses and any evidence.

3. If you don't get a satisfactory response, request outside mediation from your state ombudsman's office (www.ltombudsman.org/static_pages/ombudsmen.cfm). After an ombudsman is appointed, he or she will talk to you and nursing home personnel to try to resolve your differences amicably.

4. If the problem's still not settled,

contact your state Department of Health. Provide a detailed, documented summary of your complaint. The state will then dispatch inspectors to investigate your claims. If you disagree with the findings, you may need to hire an outside attorney and file a lawsuit.

5. Establish an independent family council with other residents' relatives so that you can voice your concerns collectively. The National Citizens' Coalition for Nursing Home Reform (NCCNHR) offers advice on how to get started (www.nccnhr.org/public/50_152_430.CFM).

6. After you complain, be extra-vigilant and document reprisals. If you suspect retaliation, consult an independent advocate. NCCNHR's Web site offers a list: www.nccnhr.org/static_pages/citizens_groups.cfm.

the authority to issue sanctions or close a facility. To substantiate a claim, the department will launch a surprise inspection of the home in question. (Nursing homes are subject to unannounced inspections every 12 to 15 months, regardless of whether a complaint has been lodged.) But critics claim investigators often lack the time and skills to discover and document violations.

No one knows that better than Brenda Durant, a 58-year-old former circuit board designer from Granbury, Texas, who from 2001 to 2004 fought a succession of nursing homes in the pursuit of competent care for her Alzheimer's-stricken mother. At each home Durant says she followed the protocol, complaining about the inadequate care she felt her mother received—whether it was being overmedicated, unnecessarily restrained, left to soil herself or otherwise neglected or mistreated—to nursing home administrators and then to state-level authorities. Durant was banned from each home and, she says, the inspectors the state dispatched failed to substantiate her accusations of poor care. Only one person in authority took Durant's side. State investigator Donna du Bois, who was assigned to review the state's findings, determined that the state's initial investigations had been flawed and, after looking further into the matter, came to believe that many of Durant's allegations were correct. Among other problems, she found that the home had not justified its physical and chemical restraint of Durant's mother. "I was totally disgusted with the state's effort," du Bois said later. "Their investigation wasn't at all thorough. They never are—investigators don't want to find problems because that means more work. The deck is stacked against people trying to

protect their families." (Du Bois no longer works for the Texas Department of Human Services; she does legal nursing consulting.)

Despite du Bois's support for Durant's claims, the investigator says the State of Texas never acted on her recommendations. In June 2003, a state official wrote to Durant saying some concerns about the investigation had been noted and were being addressed. Durant's mother later died in a nursing home.

Toby Edelman, an attorney with the Center for Medicare Advocacy, in Washington, D.C., charges that state investigators often lack the time and experience to find and document mistreatment. "They're mostly nurses who don't have a lot of investigative skills," she says. In a report this past January, the U.S. Government Accountability Office agreed, charging state investigators with often overlooking potentially life-threatening problems.

Federal oversight records seem to reflect this, too. In 2004, only six U.S. nursing homes were closed for serious deficiencies, according to the Centers for Medicare and Medicaid Services (CMS). That same year, the federal government collected only 41 percent of the \$81.7 CONTINUED ON PAGE 110

million owed in fines for two years of quality-of-care problems. "The agency's goal is not to close homes, but to improve the care they offer," explains Mary Kahn, a Medicaid specialist in the CMS public affairs office. But lax enforcement can allow offenders to operate without punishment.

HELP FOR FAMILIES

In the face of these problems, some nursing home families are taking collective action to enforce their rights and spur positive change. Federal law allows the relatives of nursing home residents to form independent family councils. But only 41 percent of nursing homes have established such councils, and just starting one independent of the nursing home administration may result in repercussions. When Harry Kornblau, whose mother was a resident of the Daughters of Sarah Nursing Center, in Albany, New York, formed an independent family council there, he says he was accused of harassing the staff and his visits were severely restricted. In late 2003 he enlisted the aid of a New York

state assemblyman to introduce legislation to protect council organizers against such reprisals. Even after his mother's death, in 2004, Kornblau lobbied tirelessly for the bill. Last year the measure was enacted in New York, requiring facilities to respond to concerns within 10 working days and prohibiting retaliation against family council members. New York joined only four other states—California, Maryland, Minnesota and Massachusetts—with such protections.

As the elderly population grows, cases of nursing home retaliation are likely to increase. The rising tide of complaints may serve to raise the quality of care at nursing homes, or it may mire many families in reprisals and restraining orders. "We've got to make sure that family members have complete access to their loved ones," warns Congressman Waxman. "Otherwise, when retaliation happens, no one will ever know what's really going on in nursing homes."

Martha Deaver, the Arkansas woman who was kept from her mother's side near the end of her life, wants to be sure Americans no longer have to suffer the way she and her mother did. Deaver began helping others file complaints against abusive and negligent nursing homes and now serves on the board of directors of the Arkansas Advocates for Nursing Home Residents, a nonprofit that aims to protect and improve residents' quality of care. "She's a tiger when fighting for patients in nursing homes who might not otherwise have a voice," says Mike Beebe, Arkansas attorney general. "She believes she has a calling to protect the vulnerable in our nursing homes."

This fall, the NCCNHR presented Deaver with the only national award regularly given to a citizen advocate for her work helping more than 100 families fight nursing home abuses. "Someone has to hold nursing homes accountable," Deaver says. Filing a grievance is often just the beginning of a long, emotional battle, but with advocates like Martha Deaver on their side, families can feel a little more secure about standing up for their loved ones. CONTINUED

THE NEW AND IMPROVED NURSING HOME OF THE FUTURE

Eighty-three-year-old Cynthia Dunn considers herself lucky. Her former nursing home, the Cedar Health Center, in Tupelo, Mississippi, was a traditional facility that featured long, sterile linoleum hallways and meals served on hospital-style trays. She shared a room with a woman who rarely spoke. "I like a little company," Dunn says, "so it was hard."

But in 2003 Dunn moved two blocks away to Franks House, a ranch-style house that she shares with nine other residents. She has her own antiques-filled bedroom and a private bathroom, where she enjoys bubble baths in a whirlpool tub. There's a garden she can putter in and a community kitchen where she can whip up her coconut cakes. When she needs help getting out of her wheelchair, specially trained nurses are there, responding to beepers, not noisy bells. "This is just a wonderful place," Dunn says. "I recommend it to all my friends."

Franks House is part of the Green House Project (www.thegreenhouseproject.com), which is only one of several innovative efforts now under way to reinvent the nursing home. Over the past decade, a grass-roots movement, including academics, gerontologists and nursing home reformers, has begun to create kinder, gentler habitats for seniors. Several hundred of these new nursing homes are already operating, and hundreds more are set to open by 2010. Their creators believe that in 20 years, these models will be the norm. "These homes are the first wave in creating the future," says Rose Marie Fagan, executive director of the Pioneer Network, in Rochester, New York, a nonprofit group that supports the reforms. "They share a belief that elderly people deserve to live in a home where they can still grow and learn and be part of the community."

One of the better-known experiments, Eden Alternative (www.edenalt.com), in Wimberley, Texas, has rejuvenated 230 nursing homes with activities designed to combat the loneliness and helplessness that plague residents in traditional homes. Eden homes bring in pets, plants and children to make the environment more lively and cheerful for the residents — known as "elders"—and enliven their routines. "Rather than just staring blankly into space, the elders are involved in painting or gardening or cooking," says Sandy Ransom, the vice president of Eden's board of directors. "They're not warehoused; they have lives worth living."

The Wellspring Program (www.wellspringis.org) emphasizes a cooperative management style at its 36 nonprofit nursing homes. Certified nurse's aides are given extra training and time to care for residents, creating closer bonds and reducing neglect and abuse. "The relationships between caregivers and residents are intense," says Tom Lohuis, CEO of the Wellspring Program. "At the Wellspring home where I used to work, caregivers would come in on their day off with babies and pets to share with residents."

The reformers do face challenges. Although services at the pioneering facilities cost roughly the same as at traditional nursing homes, operators frequently face higher insurance costs and resistance from administrators opposed to giving more decision-making power to nurses and residents. But the improved staff retention saves money.

Then there's the benefit to residents and family members. A two-year study of five Eden homes by the Texas Long Term Care Institute reported that they offer quantifiable advantages, such as a 57 percent decrease in bedsores among residents and a 44 percent

decline in staff absenteeism. An ongoing study comparing Green Houses with traditional nursing homes has found that the innovative group houses have more satisfied residents. "They flourished in the Green Houses in ways beyond the imagination that they did not in traditional nursing homes," says Rosalie A. Kane, Ph.D., a professor of public health at the University of Minnesota, in Minneapolis, who is conducting the study, funded by the Commonwealth Fund.

You can expect even more innovation in the future. Already, seniors themselves are banding together to form cooperative developments, like Glacier Circle, in Davis, California, which will house 12 residents in townhouses around a "common house" where they will share meals, activities and a nurse's care for any medical needs. Similar communities are springing up around the country. Beacon Hill Village, in Boston, was organized by a group of seniors who wanted to remain in their own homes; the nonprofit arranges for necessary services and transportation to come to them. (For the group's manual on how to set up such a community, write to Beacon Hill Village, 17 Myrtle Street, Boston, MA 02114.) Some other locales may offer "life leases," which let seniors buy into retirement communities and receive back most of their investment if they need to be transferred to nursing home care.

What these disparate groups share is a creative interest in improving the options available to seniors. "We see ourselves as pioneers for future nursing homes," says Jude Rabig, national director of the Green House Project, in New York City. "We hope to change long-term care in this country by focusing on the experience of the individual, one nursing home at a time." —M.J.W. ♥