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## Who's watching mom?

BY KAY HARVEY PIONEER PRESS

One couple that advocated for their mothers' care in a nursing home ended up with a restraining order against them.

Gertrude Matzek liked having breakfast in her room in the Hudson, Wis., nursing home where she lived.

Her son was usually there to help. Norm Matzek removed the plastic covers on her food tray, a task his mother could no longer do.

"I would help her with the little things," he recalls. "I'd clean her glasses. I'd help her put her hearing aid in if she was having difficulty that day. It was 45 minutes of quality time we had together."

Their morning ritual ended abruptly when Christian Community Home obtained a temporary restraining order against Matzek and his wife, Shirley, whose mother also lived at the home.

The order required the Matzeks to call ahead and check in and out of the facility, restricted their ability to talk with other residents and families and designated specific hours they could be on the premises. "I never again was allowed to be with my mother at breakfast time," says Norm Matzek, a retired business analyst.

The Matzeks say they just wanted quality care for their moms. The couple vocally advocated for their mothers' care and formed a family council of 15 people with relatives or friends in the nursing facility.

The nursing-home administrator portrays the Matzeks differently — as intimidating and disruptive. The nursing home accused the couple of harassment.

The Matzeks are like many families with loved ones in a home. They felt they had to represent their mothers and push for quality care. But when they did, they felt they met with retaliation from the nursing home. Although retaliation was never proven in their case, fear of retaliation is widespread, according to state ombudsmen for the nursing-home industry.

"It seems like we're hearing more and more about these kinds of cases," says Janet Wells, policy director for the Washington, D.C.-based National Citizens' Coalition of Nursing Home Reform. Some facilities use legal action. "Sometimes, it's just warnings. Some people feel pressured when warned. People have always had some concern about retaliation, mostly toward the resident. I think what we're seeing now is retaliation directed at family members."

While the Matzeks saw themselves as advocates, Dan Goodier, the home's executive director, saw their conduct as "troublesome," he said in a written statement to the Pioneer Press. Several nurses and aides at the home testified that the couple's complaints and scrutiny threatened and upset employees, he said.

"The behavior resulted in several staff members refusing to work on the units where the family's relatives resided and others threatening to quit," he said in the written statement.

As more members of a vocal baby-boomer generation — now ages 40 to 59 — become advocates for aging parents, Wells and others focused on the issue expect demands for quality care will grow.

### AFTER THE FALL

Norm and Shirley Matzek hired a lawyer to defend themselves. They talked with agencies that promote seniors' rights. And they captured attention of national advocacy groups interested in long-term care.

They learned they weren't alone. After their story of restricted access to the nursing home appeared in the November issue of the AARP Bulletin, dozens of people posted their experiences and sympathetic messages on an online message

board. The Matzeks received dozens of phone calls and letters from 20 states, some telling of similar experiences. Some asked for their advice.

For the Matzeks, the first significant concerns about his mother's care came in July 2000, when Gertrude Matzek suffered a fall at Christian Community Home in Hudson.

An aide forced her to walk even though she had a fractured hip, the couple says. They didn't learn of her injury, which they say happened early in the day, until they stopped to visit after work hours.

"She was in a lot of pain," Norm Matzek recalls. A doctor diagnosed a dislodged hipbone and internal bleeding and suggested she might never walk again.

When the couple met later with three administrators at the home, they expected an apology or acknowledgment of the error. Instead, "they told us there was no fall," he says. "These three key people said nothing was wrong. That everything was OK." The couple's reaction, he says, was "absolute disbelief."

The nursing home's Goodier said in writing that confidentiality laws prevent him from addressing any incident involving a resident's care.

Norm Matzek's habit had been to visit the nursing home at least once a day. After Gertrude Matzek's fall, she became wheelchair-bound and needed even more of their support, the couple says.

Shirley Matzek was employed at Christian Community Home as an administrative assistant to Dan Dixon, the nursing home's former executive director. In seven years in that job, she kept the records of her near-perfect evaluations.

Five months after Gertrude Matzek's fall, Shirley Matzek was reassigned to a "lesser and poorly defined job," a move that never was fully explained, she says. A few months later, she voluntarily left the nursing home for a job elsewhere.

Shirley Matzek's employment played no part in the nursing home's legal action against the couple, Goodier says. "We took action for harassment. We took it where we thought it needed to be, which was in court."

On several occasions, the Matzeks say, staff members suggested they might want to move their mothers to another facility. But the couple, who live in Hudson, valued proximity to Christian Community Home, Hudson's only nursing facility. They lacked confidence another nursing home would be better.

And they expected their mothers' adjustment to a new place would be jarring, a phenomenon people in the field call "transfer trauma."

## **QUALITY-CARE ISSUE**

Given the complexities of human nature and nursing-home care, solutions for quality-care issues seldom are simple. Staffing is a critical issue, says Wells of the nursing home reform coalition.

"Families want good care. But the way most nursing homes are staffed, they simply aren't able to provide the care some families are demanding."

The quality-care issue extends beyond a staffing shortage and individual nursing facilities, says Kathleen Kelso, executive director of the ElderCare Rights Alliance, a nonprofit agency in Minnesota that advocates for nursing-home residents and their family members.

People in the nursing-home industry often say they hear only from consumers who aren't satisfied, she says. "Maybe that's true. But I haven't heard a hue and cry that living in a nursing home is great. Yet, it might be some people's only option for what their care needs are."

The alliance is pushing for laws that demand better staff-resident ratios and intensive mandatory training for nursing assistants, she says. The organization also provides a training program for family members in navigating the long-term-care system.

What's needed most, she says, is a greater state investment in long-term care, including leadership to help craft a workable plan as growing numbers of Americans get old.

"People are stuck with whatever (facilities or services) they can find in some places," she says. "There are many gaps in service," including underfunding of home health care. That's the message the alliance plans to take to the Minnesota Legislature this year. Minnesota isn't alone, she adds, in its need to improve care for the elderly.

Dr. Robert Kane, a physician, researcher and expert on nursing-home care at the University of Minnesota, calls the nursing-home industry "a whole system that's broken." He and others in the university's School of Public Health are studying the industry, he says.

He claims money isn't the answer. The problems lie instead with an industry mind-set that's been shaped by a highly regulated industry in which homes can be fined for breaches in residents' care.

"When they (nursing homes) look around and ask, 'What should we work on: Reducing the rate of pressure sores or improving the ambience of the place or doing something that affects the quality of life?,' they'll go for the one that keeps them out of trouble."

He's hoping for a more creative approach to how nursing-home workers' jobs are structured and use of other available resources.

"We need to change the nature of accountability," he says. It's a time when hospitals are admitting their errors, he points out. "The first thing everybody says is we can't solve it by regulation. It's a whole different premise from a regulatory, policeman attitude. It's moving to a mode that says we all need to take ownership of the problem."

While the industry is highly regulated, one lawmaker has publicly charged that laws and rules designed to regulate nursing-home care aren't routinely enforced.

"We continue to hear that state inspectors understate the existence of serious quality-of-care problems," wrote Sen. Chuck Grassley, R-Iowa, a former chairman of the U.S. Senate Committee on Aging, in a letter last July to the Centers of Medicare and Medicaid Services.

Some advocates for high-quality care are putting their hopes in a movement for culture change in the industry. Sharon Zoesch, ombudsman for Older Minnesotans, defines it as organizational change that looks at life in a nursing facility "through the residents' eyes."

"We're talking about person-centered care," says Kelso of Minnesota's ElderCare Rights Alliance. "It's not about offering five meals a day or what's hanging on the walls. It's about care."

The alliance plans a conference focused on the culture of care in October. The Twin Cities' nursing-home trade organizations, Minnesota Health and Housing Alliance and Care Providers of Minnesota, offered a track on culture change as part of a conference this month. A few nursing homes in greater Minnesota already are trying to implement the change, Kelso says.

"We're trying to get this noticed," she says. "It's about caring as a culture, not something you have to do because the regulations make you do it. Some people call it nursing-home reform. But we call it the culture of care."

## FEAR FACTOR

Norm and Shirley Matzek drew attention because of the legal action against them and their willingness to talk publicly about it.

Most people in disputes with nursing homes haven't talked openly about them, says Toby Edelman, senior policy attorney with the Washington, D.C., office of the Center for Medicare Advocacy. "You don't hear about these kinds of cases until they're over."

Two national organizations, AARP and the National Citizens' Coalition of Nursing Home Reform, showed their alignment with the Matzeks by filing an amicus curiae brief in the couple's case. A federal law, the brief reiterates, gives family members round-the-clock access to nursing facilities.

The Matzeks' mission picked up steam when they participated in a panel discussion on retaliation at a NCCNHR meeting a year ago. Edelman was struck by the audience response. "I turned around and looked, and people were nodding," she says.

The couple's experience has motivated advocacy and legal groups to discuss how they might address the retaliation

issue. Even though retaliation toward residents is prohibited by federal law, most family members of nursing-home residents are afraid to complain, she says. She finds that disturbing.)

In western Wisconsin, where close-knit small towns dot the landscape, people see a nursing home as part of the community, says Robb Jirschele, regional ombudsman for nine counties in the northwestern part of the state. Most family members look outside the facility for help with concerns "only when they feel they've come up against a wall," he says.

Those who contact an ombudsman often ask to remain anonymous, says George Potaracke, director of the state ombudsman's office in Madison. Nursing-home administrators sometimes exhibit reluctance in revealing certain information, too, he says, because they fear fines that can be imposed by state regulators. "So, the notion of fear permeates the system."

In her role as ombudsman for older Minnesotans, Sharon Zoesch notices family members often find it easier to bring up concerns as part of a family group, an informal group that bands together or a family council. A federal law allows family councils to form in nursing homes to point out problems and suggest ways to improve care.

In some complaint cases, nursing-home administrators don't respond, Zoesch says. But key people in most nursing facilities put a priority on good customer relations, she says, even when nothing is wrong with the services they provide.

"I think most facilities recognize that when you take someone in, the family is an integral part of that, not just the resident," she says. "They work hard to work with families and respond to families."

## **EXPECTATIONS AND REALITY**

Whether retaliation is real or imagined, fear of retaliation probably stems from nursing-home residents' dependence on others, says Paul Mikelson, president and CEO of Lyngblomsten Care Center in St. Paul. "When I put that light on, will they come? That's a very normal fear to have."

In Minnesota and Wisconsin, law requires all nursing-home employees to complete training in care of vulnerable adults. Employees could be disciplined or fired for acts of retaliation against residents, Mikelson says.

He calls fear of bringing up concerns unrealistic and unproductive. "That kind of feedback is necessary," he says. But it's important that residents and their families understand nursing homes aren't staffed to operate like hospitals, he says. "Sometimes, a difficult situation can arise when expectations and reality don't meet. Usually, those things can be worked out."

Still, Zoesch sees family members' fear of complaining as pervasive, she says. It's not just Minnesota nice. "Everybody's fearful that if they complain too forcefully, subtle kinds of retaliation will be taken out on their loved ones," she says.

While nursing homes occasionally issue restraining orders for threatening behaviors, the Matzeks' case is the first she knows of based on complaints about care. But she acknowledges that complaining can be risky business. When relatives repeatedly voice concerns — legitimate or not — they may be labeled as frequent complainers, she says.

"Then, the staff tunes you out or doesn't listen to you. The worst-case scenario is when a facility suggests a resident move to another place because they don't want to deal with the family anymore."

## **COMPLAINING, RESTRAINING**

Gertrude Matzek died at age 100 in her nursing-home bed on a March night in 2003.

Erma Stock, Shirley Matzek's mother, continued to live at the home.

As Shirley's mother's health began to decline, Norm Matzek stopped by Christian Community Home to feed his mother-in-law two or three meals every day.

By that time, the couple's request to the judge in their case had restored their visitation to the nursing home to include breakfast time, though other time limits in their restraining order remained.

Shirley Matzek continued to diligently advocate for her mother's care. "When there was something of concern, we learned to put it in writing," she says.

The nursing home responded to all complaints regarding their mothers' care, Goodier says. The couple disputes that, saying they were "amazed" when the facility didn't address their concerns. Over four years, they sent their mothers' complaints about care to the facility and the Bureau of Quality Assurance (BQA), the state agency that regulates Wisconsin's nursing homes, they say.

Court records and complaints filed with the BQA show that, in addition to Norm's mother's fall, the Matzeks cited concerns about overmedication, a bed sore, dehydration, weight loss, cold showers and delayed response to call lights and toileting needs.

Shirley Matzek once found her mother's bed "crawling with ants" and no one on staff to find a solution at the time, she wrote in a complaint. The nursing home countered as part of a BQA investigation that staff members had responded to the problem.

On one occasion, Shirley Matzek and her husband were made to wait outside the door of her mother's room for 45 minutes, they said, as her mother screamed and cried out repeatedly while being readied for bed, according to a staff member's written account in court records. Court records show they were told they needed a nurse's OK to be in the room, given conditions of the restraining order. The restraining order appears to list nothing to bar their presence in a situation of that sort.

Nurses and assistants at the nursing home said they felt intimidated by the couple's watchfulness, according to court records in the case. Some said Norm Matzek questioned staff about delays in responding to call lights. "It was like walking on eggs" when the Matzeks were present, one employee testified.

The BQA responded to the Matzeks' mothers' complaints by deeming each of them "unsubstantiated," the Matzeks say. "Unsubstantiated" means "we could not verify that it happened," though it may have, says Joe Bronner, field operations director of the agency's Western Regional Office in Eau Claire, Wis.

As Shirley Matzek was arriving home from work one summer day last year, a process server appeared at the couple's door notifying them her mother would be involuntarily moved from Christian Community Home within 48 hours. The Matzeks were able to avert that order by retaining an immediate injunction against the nursing home. Such an order, they learned, is unlawful; a 30-day notice is required.

They believed retaliation against Shirley's mother, who was blind and used a wheelchair, was escalating. Care issues were increasing, they say. In October, Shirley Matzek and her sister moved Erma Stock to a Minnesota facility. After almost two years, the temporary restraining order was lifted.

Later moved to another home in western Wisconsin, Erma Stock died there five weeks after leaving the Hudson facility. "We believe my mother died of transfer trauma," Shirley Matzek says.

Altogether, the couple spent more than \$30,000 in legal fees in an attempt to defend themselves against the restraining order.

In his written statement, Goodier wrote that investigating the couple's allegations of inadequate care resulted in "a tremendous cost of facility staff time and taxpayer dollars." He said no significant resident-care issues ever were confirmed.

"We used the system," Norm Matzek says. "We filed complaints like you're supposed to. And look what we got as a response."

The couple persevered, bolstered by what they call their "moral courage" to preserve the voice of the elderly. They hope their story will encourage other people to speak out for quality care in America's nursing homes.

"It's such a David and Goliath situation," Norm says. "But we can't keep our heads in the sand. We're one of the richest countries in the world. Can't we do better for our elderly?"

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Kay Harvey can be reached at [kharvey@pioneerpress.com](mailto:kharvey@pioneerpress.com) or 651-228-5468.

<http://www.twincities.com>