Dementia homes exist in gray area of regulation, families say

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When Mary Taylor suffered a stroke in March 2010, her mental state declined quickly.

The retired Redstone Arsenal budget analyst from Huntsville had hallucinations that helicopters hovered outside the window of her nursing home. She couldn't remember meals five minutes after she'd eaten them, her daughter said.

Mary Taylor of Huntsville wanted to go home, but her daughter Pam quickly realized she couldn't.

"At that point, honestly I did not know about assisted living," Taylor said. "I did not know about assisted living for people with dementia, I knew none of this. We looked into possibly getting some home health and some visiting nurses. But that at least short term was not going to work."

Assisted living appeared to be the best option, Taylor said. Friends recommended Agape Village, an assisted living facility designed for residents with dementia.

What questions should you ask at assisted living facilities? [http://www.al.com /news/index.ssf/2016/01/how_to_find_the_right_dementia.html#incart_article_small]

[http://www.al.com /news/index.ssf /2016/01 /how_to_find_the_righ t_dementia.html#inca rt_article_small]

[http://www.al.com/news/index.ssf/2016/01/how_to_find_the_right_dementia.html#incart_article_small]

The facility opened in Hazel Green decades ago, by a nurse with a family history of Alzheimer's disease. For years, the original owner and her family operated the facility, but she later sold it to Great Oaks Management, an assisted living company based in Montgomery.

Unlike a nursing home, this assisted-living facility promised a homelike environment and just enough help with medication and other tasks to keep Mary Taylor safe.

The state of Alabama passed regulations creating specialty-care assisted living facilities in 2001, and immediately converted about a third of assisted living beds into dementia care. Since then, the number of beds available in the state for dementia patients has hovered between 2,500 and 3,000, said Frank Holden, president of the Assisted Living Association of Alabama.

Assisted living facilities receive less regulation than nursing homes because they don't receive much funding or oversight from federal programs such as Medicare.

Both are inspected by the Alabama Department of Public Health, but the nursing home division has about 40 inspectors covering some 300 facilities. The assisted living division, which includes the specialty care facilities, also handles about 300 facilities, but

with seven inspectors, said Dr. W.T. "Tom" Geary, medical director of the Bureau of Health Provider Standards.

Check here to find out if a facility has been cited by state regulators

Online Database [http://www.caspio.com] by Caspio

Specialty care assisted living facilities can be cited for failing to respond properly to incidents that threaten the health and safety of residents. Search by facility name to find out whether a dementia care home has been cited since 2005. Special note: Sexual and physical abuse can include episodes between two residents or residents and staff.

Facility

Search

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Source: Alabama Department of Public Health

Specialty-care assisted living facilities fall into a kind of gray area between regular assisted living and nursing home care. Residents often can't communicate basic needs and require supervision in locked facilities, but they don't need the kind of medical care provided in a nursing home.

The quality of care can vary significantly from one facility to another. The best assisted living facilities provide comfortable and healthy homes for patients in early and moderate stages of physical and mental decline. But inspection reports reveal that many fail to adequately staff facilities and train workers caring for patients – leading to falls, errors, abuse and even death.

About a year after Mary Taylor moved into Agape Village, her health took an unusual turn.

"I called that morning to check on mama, and they were laughing kind of about she was talking real funny and making cat noises and wasn't making a lot of sense," Taylor said. "So I got on the phone with her and listened for a minute, hung up, Googled the symptoms and realized she'd had another stroke. They didn't know that there, so she sat there for hours like that until I called back and said, 'Call an ambulance. Get her to the hospital.'"

Even though employees missed the signs of the stroke according to a lawsuit, Mary Taylor returned to Agape after she left the hospital. Soon after the returned, the facility seemed to slide downhill, Taylor said. Old staff members left and new ones appeared. Agape admitted residents who screamed and harassed others in the building, she said.

Taylor began to look for a new home for her mother. Many of the facilities close to Huntsville had waiting lists, and she worried about the impact of a move on her mother, who already struggled with confusion.

She said decided to reach out to administrators to try to improve conditions in the facility, but instead, things only got worse. Taylor spotted rats and mice in the facility. The facility was cited by the health department because employees failed to keep one resident from repeatedly urinating in common areas.

Taylor's frustration boiled over in August 2012. When Taylor visited her mother, she discovered the air conditioning had broken. When she returned a few days later, it hadn't been fixed, Taylor said.

During this time, she reached out to another woman whose mother lived in the facility, Melody Gill. Her mother, Elaine Gill, had been falling – a lot. She fell so often at Agape that inspectors cited the facility for failing to protect her, according to documents from the Alabama Department of Public Health.

In November 2012, Gill received the call that her mother had fallen in a closed courtyard early in the morning.

"I dropped everything and went over, and she just looked like she'd been in a fight," Gill said. "Her whole face was bruised, both sides of her face. And over her eye was a massive gash. Her hands were gashed and bruised."

Gill drove her mother to the emergency room and held her down while she received stitches, she said.

"I cried the whole time," Gill said.

Gill began to suspect that some of her mother's injuries weren't caused by falls. She and Taylor began talking about their concerns. They called corporate offices, and eventually they reached out the ombudsman, an official who investigates complaints against long-term care facilities in Alabama.

In September 2012, officials from the Alabama Department of Public Health investigated their complaints, gave the facility a failing grade and demanded a plan of correction.

Inspectors typically inspect facilities once every three or four years, Holden said, or whenever there is a complaint. More than 100 deficiency reports posted online reveal that facilities are most often cited because they don't have enough staff, and for failing to properly hire and train employees who work with residents.

Even in facilities that have not lost licenses, serious lapses have occurred. Many facilities kept residents whose needs exceeded the capabilities of assisted living and should have been transferred to nursing homes.

Residents have escaped from locked facilities. Employees have forged physician orders and committed medication errors. In one case, a facility was cited for two deaths that occurred because employees failed to call 911.

Agape Village ultimately lost its license to operate a specialty care assisted living facility, after a follow-up inspection in December 2012 revealed that little progress had been made to clean up the home. Families of residents, including Gill and Taylor, filed a lawsuit. One employee was charged with abuse and neglect of two residents at Agape.

In the final deficiency report, inspectors said administrators at Agape Village and executives at Great Oaks Management didn't properly report suspicions of abuse, and yet many of those administrators never faced any sanctions and continue to work in assisted living, Gill said.

"They are still driving their Porsches and going to their lake houses, and it's all on my mother's dime," Gill said.

Gill and Taylor are pushing for changes. They want tighter regulations on dementia care facilities and more rigorous background checks for employees. State regulators have no ability to fine facilities for deficiencies, although they can impose civil penalties on individuals who break state law. The process for revoking a license can go on so long that some facilities simply sell the license to another business, effectively escaping any punishment at all, Gill said.

"Agape would not have ever been shut down if we had not done something," Taylor said.

The facility formerly known as Agape Village is still owned and operated by Great Oaks Management, the company in charge during the final troubled years of its existence. Now it is a regular assisted living facility called Gardens of Madison. Company executives didn't respond to requests for comment.

Holden of the Assisted Living Association of Alabama said dementia care facilities don't need more regulation.

"I would argue that the regulatory scheme in Alabama is about right," Holden said. "I would like to see more frequent inspections. We are looking at a survey cycle of about 48 months and that's not good. Every 18 months would be better."

Even with fewer inspectors, the assisted living division has terminated the licenses of 20 homes for dementia patients in the last decade. Just four nursing homes have been shut down in the same time period, Geary said.

Matt Minner is an attorney at Hare, Wynn, Newell and Newton who represents families in elder care litigation. He was not involved in the lawsuit against Great Oaks Management and Agape Village, but he is familiar with assisted living regulations in Southern states. Alabama has some gaps in regulations, he said.

"You can run an assisted living facility without insurance," Minner said. "Are you kidding me? You can't drive a car out here without insurance. And you see that corporate design more frequently out here than I would care to talk about. It means there's nothing you can do if your loved one is ever injured."

Troubled facilities can easily avoid closure by selling a license or changing formal ownership, he said.

"They can switch the name of the nursing home with a few corporate documents and a corporate lawyer pretty quickly and the entity you had the problem with is no longer in existence," Minner said.

Still, Holden said Alabama requires more training for caregivers than many other states, and adopted those regulations early on. Most of the training materials were developed by dementia experts from UAB and the Alabama Department of Mental Health, he

said.

The dementia care business in Alabama has been slow to grow because the state limits the number of beds, Holden said, but the need for such care is growing. The World health Organization predicted the number of dementia cases would triple worldwide by 2050.

"Dementia as a whole is on an alarming increase," said Dr. Kathleen Fix, a specialist in geriatrics at UAB. "It's a very obvious oncoming problem that I'm not sure we're well prepared for."

Dementia is very costly to families. Many people cannot care for a parent with dementia because they need constant supervision, and in many cases, assisted living facilities provide crucial care.

Rent at dementia care facilities can cost thousands of dollars a month. Taylor paid $3,600 a month to keep her mother at Agape. The family sold her mother's house, car and used her savings to pay for care.

Her mother left Agape in December, right before the facility lost its license. She eventually landed in a nursing home in Tennessee, where she spent the final years of her life. Mary Taylor died in March 2015.

"She was a strong intelligent woman," Taylor said. "That the last years of her life had to be like that was very painful for anyone who loved her."

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