

## Family councils advocate for relatives in nursing homes

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The relatives of Texas nursing home residents have discovered there's strength in numbers. Emboldened by a new state law, they've begun to organize more "family councils" at their nursing homes to advocate for better care.

"My mother was the one who taught me how to stand up and speak out, so it's only fitting that I now step in for her," said Daisy Kincheloe, who knew she had to do something after her elderly mother fell at Doctors Healthcare Center in North Dallas.

Her mother's accident was the last straw. Before that, she had discovered other problems that convinced her that some staff members weren't paying enough attention.

Ms. Kincheloe and other families at Doctors have just formed the group to give each other moral support, act as added sets of eyes and ears around the nursing home, and bring grievances to the administration's attention.

By presenting a united front, family councils have persuaded nursing homes to respond more quickly to residents' call buttons, improve the meals and even hire more staff, said Lou O'Reilly, a co-founder of Texas Advocates for Nursing Home Residents.

"While not a cure-all, they do make a difference," she said.

Family councils are enjoying renewed attention nationwide because many of their newer leaders are baby boomers, whose generation is known for its activism, said Mary Brown, an official with the Elder Care Rights Alliance.

"A changing of the guard is under way," she said. "The new leaders see their councils as more than just support groups for families. They have ambitious agendas."

Though administrators occasionally resist the councils at first, a growing number say they welcome the groups because they encourage family participation and accountability from staff.

"Our biggest problem is a lack of family involvement. No visits. No calls. It's good to have a core group of committed relatives to give us feedback," said David Thomason, senior vice president of the Texas Association of Homes and Services for the Aging.

Personal touch

**Family councils also fit well with the industry's larger effort to transform long-term care and make nursing facilities less impersonal, said Tim Graves, president of the Texas Health Care Association.**

Though a 20-year-old federal law first gave families the right to create nursing home councils, a new state law raising the councils' profile and bolstering their influence has energized advocates and sparked interest among families.

The measure, introduced by state Sen. Royce West of Dallas and approved last year, will help councils recruit members and find out sooner about health or safety violations uncovered by the state's inspection team.

"We all know we have problems in nursing homes," the Democratic lawmaker said. "The new law, I hope, will foster better cooperation and ultimately better care."

Families are starting councils at six Dallas County nursing homes, said Suzanna Swanson, director of the local long-term care ombudsman program. With those additions, there will be groups at 23 of Dallas County's 61 homes.

"The councils offer families a better way to express their concerns," Ms. Swanson said.

Ms. O'Reilly said many families hesitate to bring up problems because they're afraid the nursing home staff will retaliate against their relatives. Others complain but find their grievances fall on deaf ears.

A family council can add weight to a complaint, advocates say.

"If one person says, 'My mother's call button wasn't answered,' nothing may happen. But if a half-dozen say so, the nursing home will know it has a systemic problem on its hands," said Ms. Brown of the Minnesota-based Elder Care Rights Alliance.

Councils usually meet for an hour once a month at the nursing home. The law stipulates that the staff may only attend at the council's invitation.

At Cross Timbers Rehabilitation and Healthcare Center in Flower Mound, a dozen family members gather monthly. That represents a tenth of the facility's families, which advocates say is an average turnout.

Belonging to families

"It's the families' meeting; they set the agenda and run it. Staff comes only to answer questions or explain new programs," said administrator Tod Mahoney.

Some family councils get off to bumpy starts.

Gary Rigsby, who helped organize a council last year at his mother's nursing home, Castle Manor in Garland, said he butted heads with an administrator.

"The previous manager didn't know what to make of the council," he said. "Fortunately, the new one understands we're all supposed to be on the same team."

Effective family councils build trust with management, said Patty Ducayet, director of the state's ombudsman program.

"Council meetings shouldn't be just gripe sessions," she said.

Ms. Kincheloe said the council meetings she's organizing at Doctors Healthcare Center will bring in experts to talk about Alzheimer's disease, family caregiving and long-term care insurance.

She also expects the council to sponsor birthday lunches for residents and plan outings to the zoo and movie theaters.

The council at Northgate Plaza Nursing and Rehabilitation Center in Irving gives the Star Employee of the Month a plaque and gift certificate.

"We've found that employee recognition is a great motivator and keeps people on their toes," said council president Theresa Rayski of Fort Worth.

Like PTAs

Sabrina Porter, executive director of Grace Presbyterian Village in Dallas, says a family council is much like "a PTA group where families and staff work together and support each other."

Thanks to a council suggestion, she said, the senior community hired a full-time chaplain. Before that, it had relied on volunteers to attend to spiritual needs.

The chief obstacle to successful councils is high turnover, advocates say. When residents move on or pass away, families lose interest.

Marilyn Darnall of Burkburnett, Texas, whose son has been in a number of nursing homes over the last 10 years, has started three councils and seen dozens of members come and go.

Still, she considers it a victory whenever a new family member attends a council meeting.

"I can't tell you how many families stop by the nursing home for 30 minutes every Sunday, and that's all you see of them. Their loved ones are left alone for the rest of the week. One by one, family councils are changing that."

## **HOW TO ORGANIZE A FAMILY COUNCIL**

- 1. Determine the need.** As few as two or three families can organize a council.
- 2. Advise the administrator.** By law, nursing homes must provide private meeting space for councils.
- 3. Notify other families.** Meeting announcements can be posted on bulletin boards. Administrators may also offer to mail notices.
- 4. Ask advocacy groups and the local ombudsman for help.** Advocates and the state ombudsman program's local representative can explain nursing home residents' rights.
- 5. Hold your first meeting.** Discuss the council's purpose, ask the ombudsman to talk about the grievance process and invite the administrator to speak.

## Resources

These groups help families of nursing home residents start councils.

**Texas Advocates for Nursing Home Residents:** 972-572-6330

**Texas' long-term care ombudsman program:** 214-823-5700 in Dallas County; 1-800-252-2412 elsewhere

SOURCE: Texas Advocates for Nursing Home Residents