

Pathfinder Care Management featured in St. Paul Pioneer Press (MN)

April 19, 2009

Section: Main

Edition: St. Paul

Page: A1

AS BOOMERS CARE FOR THEIR PARENTS, WHO WILL CARE FOR THEM? THE DEMANDS OF CARING FOR THEIR AGING PARENTS ARE PUTTING A STRAIN ON THE GENERATION BORN AFTER WORLD WAR II. BUT THE CHILDREN OF BABY BOOMERS WILL FACE AN EVEN GREATER BURDEN.

Jeremy Olson

jolson@pioneerpress.com

Maggie Jessen was once the death of her mother -- a teenage wild child who smoked and ignored schoolwork and left home at age 16 after an argument with her father.

Now, she is the lifeline keeping her 91-year-old mother, Maurine Martin, out of a nursing home.

Maurine has lived the past four years in Maggie's home in St. Paul, in a bedroom that Maggie's husband built in place of the back porch. She is forgetful and hallucinates about cats and children. Sometimes she thinks her room is an apartment and calls her daughter's house "the building."

Caring for Maurine takes energy and patience -- whatever Maggie has left after working with special-education students at Central High School. Friends tell Maggie she's "done her time," but they don't understand.

"You can't understand unless you've been through it," she said. "I mean, it's my mom!"

A cluttered nursing home may be the stereotype of elder care in the United States, but spouses, friends and adult children provide more than 90 percent of the care to the nation's frail and elderly. This informal network is the backbone of the nation's long-term-care system, and it will be needed more than ever as the baby boomers age. But studies show that caregivers such as Maggie are under strain and that the next generation will be overwhelmed.

Caregivers are prone to anxiety and depression, they suffer higher rates of injuries and chronic diseases, and they sacrifice their jobs and savings taking care of loved ones.

Perhaps the most tragic tale of family caregiving came last month in Hudson, Wis. -- when 83-year-old Claire Erickson allegedly killed himself and his wife. Erickson's son believes his father was trying to spare his children from the caregiving burden he endured for years with his 81-year-old wife, who had Alzheimer's disease.

The pressure is only going to get worse. Many of today's caregivers are boomers -- the 78 million Americans born between 1946 and 1964. But soon the boomers will need the help, and they simply didn't have enough kids -- especially daughters, who most often step into caregiving roles.

While the number of seniors increases by 2.3 percent each year, the number of likely family caregivers increases only 0.8 percent, according to Georgetown University's Center on an Aging Society.

Boomers may be expecting their children to help care for them, but surveys show that their children haven't thought much about the responsibility. Maybe they've envisioned stopping by the folks' house to change a furnace filter, but most are unprepared for the more demanding roles -- the lifting, the changing, the help with showering -- that can be required.

"The discrepancy between who they think they should be and their actual duties as caregivers can cause them great stress," said Krista O'Connor of Eldercare Partners, a grant-funded program in West St. Paul that supports and trains family caregivers. "This can come either way. They may feel stress because they're doing more than they should, or they're feeling guilt over the fact that they're not doing enough."

THE CHALLENGES

Maggie never envisioned being the primary caregiver for her mother, and yet in some ways the role was always in front of her. Her mother at different times took care of Maggie's ailing father and her grandmother. Another grandmother took care of a great-grandmother, an ornery woman who ran a turn-of-the-century boarding house for oil-field workers in Kansas.

The great-grandma used to ring a dinner bell for help. Maggie's mom has a whistle and is audible at night through a baby monitor. Many a deep sleep has been disrupted by Maurine's calls for help.

"Margaret! Margaret!"

Maurine calls for her daughter to get to the bathroom, but sometimes Maggie thinks that's just an excuse. She wishes her mother would just ask to talk, because it's hard to lift her out of bed.

Not that the transition has been easy for her mother, who spent her life caring for her family and mothering students as a secretary at Macalester College.

Maurine waters plants, washes potatoes and sorts socks to feel useful. Her need for a purpose explains why it's

hard to just ask her daughter to come into the bedroom for a talk.

"It's silly," Maurine said from the comfy chair in her room, "when you don't feel like you've got enough strength to get up by yourself and go to the bathroom."

Maurine takes an antipsychotic for delusions and needs a walker to get around. Her condition would qualify her for a nursing home. She could afford one, too. Her husband worked in marketing for The St. Paul Cos. and left Maurine financially secure.

Maggie was surprised how rapidly her mother declined after her father's death. A retirement community might have been OK for Maurine when she was in her 70s. But after a fall in her late 80s, and obvious signs of dementia, it no longer seemed like the right choice.

Maurine lives simply now.

Poor vision makes TV blurry, so she listens to books on tape and fiddles with a basket of sewing crafts. She squints at the painting of a wheat field -- it reminds her of the Kansas of her youth. And she relishes the visits from great-grandchildren. Maggie takes some relief in caring for her patient mother compared with her hardboiled dad.

"Dad wouldn't have lasted 15 minutes," she said.

Family caregiving is an enormous financial dilemma.

On one hand, even a 1 percent decline in family caregivers would generate \$30 million more in state and taxpayer spending on nursing homes and other care services. On the other, an increase in family caregiving takes people away from their jobs and erodes their productivity.

The pressure is greatest in states such as Minnesota, where two-thirds of married women are in the workplace. That's the third-highest rate in the nation. The conflicting demands of their jobs and loved ones stretch them thin.

"We have to figure out how to take care of the people who are taking care of our seniors," O'Connor said. "If their health deteriorates, then who is going to be able to take care of their loved ones?"

One role for O'Connor's organization is to assess caregivers who are struggling and identify the support services that could help them. **Other companies like Pathfinder Care Management in Minneapolis help adult children and spouses manage the care of loved ones. The company even monitors seniors for long-distance children and keeps them informed.**

State and federal lawmakers are offering solutions as well, though they may be long shots in the lean economy.

One idea is a tax credit for family caregiving. Another is to professionalize family caregivers by assessing their abilities and needs and giving them required training.

Government reforms like this that legitimize family caregiving will be essential, said Rhonda Montgomery, a caregiving expert at the University of Wisconsin-Milwaukee. "Until that time, family caregivers will continue to be the unsung and under-supported heroes of elder care."

THE ROUTINES

Maggie runs a tight schedule. Her mother promises to stay quiet in bed -- often with the family cat tucked under the covers -- while Maggie gets ready for school. A paid nursing aide then watches Maurine, often taking her to a favorite bench along the Mississippi River after lunch.

Maggie's husband, Peter, is then in charge -- usually while Maurine takes a nap -- until the late afternoon when school lets out.

A key lesson for Maggie has been to let the harmless delusions go, like when her mother watched the Olympics last summer.

"Guess where we are right now," Maurine told someone on the phone.

"Beijing!" she said excitedly.

When Maurine grew fretful because she no longer had her own street address, Maggie found a sticker with the numeral 1 and placed it on her mother's bedroom door.

Privacy is rare. Maggie doesn't argue with Peter much -- it upsets her mother -- so the stress can build.

Someone always has to be at home. Once, her sons took turns at the house while Maggie and Peter took a weekend vacation. Maggie, at 54 a baby boomer herself, wonders if her sons will care for her one day.

Sixty percent of family caregivers are women, who are more likely to take on prolonged, hands-on duties. The number of male caregivers is growing, but they tend to seek paid support services.

Experts believe both genders will have to change. Women will burn out if they don't seek respite once in a while. Men will need to pitch in more. Professional services may grow in short supply when the aging boomers flood the market.

Families spread across the country will need to talk clearly about the care needs of loved ones.

Maggie and her brother are co-trustees of their mother's estate. It's been difficult for them to always agree on the best care for their mother and how to manage her finances.

Despite the pressures, Maggie never wants her mother to move out.

After four years in one house, everyone has heard Maurine's favorite stories, especially about the old days in Kansas.

There's the one about the family Model-T and how it struggled up steep hills and over cattle grates.

There's the one about her brother firing a BB pellet into her buttock when she tried to scare away rabbits from the

hunters.

On a sunny Thursday in April, it seemed a fine time to hear them all over again. Maggie lifted her mother up to her walker, and they slowly moved through the house to the front porch.

Maggie eased her mother into an easy chair. After tying a long bib around her mother's neck, Maggie placed a bowl of vanilla ice cream on her lap.

Sitting next to her was her great-granddaughter, 18-month-old Olivia, who was enjoying a bowl of macaroni and cheese.

Maggie enjoyed the moment. It's a big reason why this has worked for so long.

"I guess, we really feel like we benefit," Maggie said, "as much as mother does."

TIPS ON FAMILY CAREGIVING

- Seek respite to reward the hard work of caregiving.
- Understand and watch for signs of depression.
- Accept offers of help and offer specific tasks.
- Learn about your loved one's condition and how to discuss it with doctors.
- Consider technologies that promote independence.
- Be good to your back. Lift with care.
- Seek support from other caregivers.
- Life changes with caregiving. Grieve for things that are lost, but remember to dream and set new goals.

Source: National Family Caregivers Association

FAMILY CAREGIVING BY THE NUMBERS

2 - times the usual rate of depression is seen in people spending at least 36 hours per week in caregiving

3 - years is the time a caregiver's immune system is diminished after caring for someone with dementia

10 - years of life are lost, on average, for caregivers who suffer extreme stress

13% of workers are caregivers

\$34 billion in U.S. productivity is lost each year because of workers who are caregivers for loved ones

58 percent of caregivers are women

\$115 BILLION was spent in 2004 on nursing home care in the U.S.

\$306 BILLION - is the estimated value of unpaid family caregiving in the U.S.

Source: National Family Caregivers Association

FAMILY CAREGIVING IN MINNESOTA

Caregivers: 503,523

Average hours a caregiver works each year: 1,070

Economic value of this unpaid care: \$5.8 billion

Source: National Family Caregivers Association

Jeremy Olson is writing a series of stories on long-term care through a fellowship with the Kaiser Family Foundation. He can be reached at 651-228-5583.

3 PIONEER PRESS PHOTOS BY JEAN PIERI

1) Maggie Jessen holds the hand of her mother, Maurine Martin, 91, while they talk on the deck of the Jessen home in St. Paul. For the past four years, Maurine has lived with her daughter and her family in their St. Paul home, in a bedroom built in place of the back porch.

2) Maurine greets her 18-month-old great-granddaughter, Olivia, and Maggie on a recent afternoon. Maggie's caregiving has allowed her mother to avoid a nursing home.

3) "I guess, we really feel like we benefit as much as mother does," says Maggie Jessen, left, of the family caregiving arrangement for her 91-year-old mother, Maurine Martin.