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Caregiving at a crossroads

Boomer caregivers drive push for more integrated support services

SAN FRANCISCO (MarketWatch) -- For years, people who cared for an infirm loved one toiled in relative isolation without much of a collective voice. But unpaid caregivers' needs are getting more attention with the rise of the baby-boomer caregiver and concern about the ballooning costs of chronic medical conditions as people live longer.

From January through June, Congress introduced 14 bills that would have a positive impact on family caregivers or the lives of those they care for, said Suzanne Mintz, president and co-founder of the National Family Caregivers Association in Kensington, Md., which began 14 years ago.

Video: Supporting boomer caregivers
Kristen Gerencher talks to aging experts about best practices for supporting family caregivers as they try to keep older relatives out of nursing homes, and how boomers may benefit.

"I think we have reached a tipping point or that we're close to it," Mintz said.

In the past few months, she's participated in a panel on chronic illness hosted by Intel and joined the advisory board of a new coalition called the Partnership to Fight Chronic Disease, headed by former Surgeon General Richard Carmona. Steve Case's new venture, RevolutionHealth.com, partners with her group as well.

"It's very exciting," said Mintz, whose husband was diagnosed with multiple sclerosis in 1974. "When we started the NFCA we had to explain to everyone what we were talking about. We definitely don't have to do that now."

At least 44 million Americans provide care for another adult. The typical family caregiver is a 46-year-old woman with some college education who provides care for a widow, according to the National Alliance for Caregiving, a nonprofit organization in Washington, which puts the market value of unpaid caregiving at $257 billion -- more than double the combined spending on nursing-home and home care.

Many boomers, who were born in the demographic bulge between 1946 and 1964, are watching their children gain independence while worrying that their parents soon will lose theirs, if they haven't already. As they prepare to face what is often an onslaught of decisions about an aging parent's doctors, medications and daily care, many discover a patchwork of fragmented services -- and a potentially hefty bill.

Between the costs, changing family structures and the growth of long-distance caregiving, it pays for adults to plan early for what services may be needed, aging experts say. And there are ways to help an older parent maximize quality of life and navigate what can be an uncomfortable transition while protecting the health of both parties.

Coordinating care

Best practices for keeping older people healthy and out of nursing homes were hot topics at the annual meeting of the National Association of Area Agencies on Aging (N4A), held in San Francisco earlier this week.

Middle-income families tend to struggle most because they don't have the means to cover the high cost of private home health aides and yet they don't qualify for low-income subsidies, said Josefina Carbonell, assistant secretary for aging for the U.S. Administration on Aging.

"We want to give those people the tools so they can manage their resources much more effectively and that we create a whole core of community-based services that are more affordable," Carbonell said at the annual meeting.

The government, which has an incentive to prevent elders from "spending down" to Medicaid, is stepping up its services under the National Family Caregiver Support Program, which targets family caregivers through the 650 nationwide Area Agencies on Aging.

Caregivers can search for services through the Elder Care Locator at www.eldercare.gov and by visiting their local N4A chapter.

The Alzheimer's Association offers support on its CareFinder tool at www.alz.org/carefinder and through a toll-free hotline: 1-800-272-3900.

As life spans increase, many caregivers are finding the problems they face are linked to those of health care generally and chronic-illness care specifically. With many older adults taking multiple prescription drugs to keep chronic conditions such as high blood pressure and diabetes under control, caregivers often are left to coordinate complicated care.

A program called Guided Care aims to address such problems by putting registered nurses in primary-care doctors' offices to work exclusively with older patients, said Dr. Chad Boult, director of the Roger C. Lipitz Center for Integrated Health Care at Johns Hopkins Bloomberg School of Public Health in Baltimore.

"There is no widespread system in which different doctors know what each other are doing with the same patient," he said.

The goal of Guided Care, which is in a five-year clinical trial, is to improve quality of life for patients and family caregivers while reducing Medicare spending. Patients with multiple health problems are especially vulnerable when they go through a transition, Boult said.

"Every time they move they get a new assessment by a new team," he said. "Many times people end up -- when they finally come home after these sets of transitions -- very confused because they have a medicine cabinet full of medicines they were taking before they went into the hospital. They don't know if they're supposed to be on the medication they were taking before, or only the new ones or both. Sometimes they're the same but have changed to brands or generics and can end up double-dosing."

Guided Care nurses also offer a short course for family caregivers on how to take care of themselves, set limits, deal with guilt and enlist other family members to prevent burn-out. There's also a monthly support group, though few have taken advantage of it so far, Boult said, noting the field of supporting family caregivers is fairly new.

"They're extremely important in the whole health-care delivery system," Boult said. "They probably do more hands-on work than anyone else.... Everyone recognizes that you have to have a healthy caregiver in order to stay in the role to provide the care."

Evolving field

The aging population also has created a new generation of "telecare" sensor and monitoring equipment for remote caregiving. At the third annual Boomer Venture Summit in Santa Clara, Calif., in June, finalists in the business-plan competitions included companies selling medication reminder software, affordable hearing-health services and a medical device to improve therapy for incontinence.

"Obviously, there are technologies that can make things easier, but it always will be a high-touch experience," said Mintz.

Some employers are starting to go beyond simple elder-care referrals and beginning to offer partial or full reimbursement for emergency home care, she said.

For families who can afford it, Tiffany Glisson, family caregiver advocate for Trident AAA in Charleston, S.C., said she makes referrals to geriatric care managers. "That's an expense most people can't afford to pay for, especially if they're supporting their parents to pay for housing or medications or someone to come into the house to provide care."

By going through an agency, home health workers typically cost $15 to $19 an hour and require at least four hours whereas a private worker would charge an hourly $8 to $10 and offer flexibility, she said.

Family caregivers' back-up labor supply is struggling to keep itself afloat. Though home health aide is the job with the highest expected growth through 2014, people who provide personal in-home services such as helping elders feed, bathe and dress themselves often receive low pay and little if any health insurance of their own.

The International Longevity Center-USA and the Schmieding Center for Senior Health & Education recently launched the Caregiving Project for Older Americans, which aims to develop affordable new approaches to in-home caregiving for older adults.

As more boomers care for their elderly parents, services such as adult day care likely will grow and become more diverse, catering to a broader range of abilities and interests, said Donna Harvey, executive director of Hawkeye Valley Area Agency on Aging in Waterloo, Iowa. In her 10-county area, just one place offers adult day care.

"We'll see new senior support services evolve over the next 10 years because we have a new population that knows they have choices and will demand them," Harvey said.