Quality Care in Challenging Times

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Coordinated care models for Alzheimer’s patients are beginning to emerge as health insurers take steps to improve care and quality of life for individuals afflicted with this insidious disease.

By Jay Greene

Every 72 seconds, someone in the United States develops Alzheimer’s disease, an incurable affliction that kills at least 66,000 people annually, making it the nation’s seventh leading cause of death. Alzheimer’s is the most common form of dementia, accounting for 60 percent of cases (5.1 million people), according to the Alzheimer’s Association, Chicago. Dementia describes a group of symptoms—loss of memory, judgment, language, and other intellectual skills—caused by damage to neurons, the brain’s nerve cells.

Geriatricians and other elder care experts are concerned that the number of Alzheimer’s patients is steadily growing and is expected to triple to 16 million people by 2050, raising questions about how to finance and manage care for this growing population and putting stress on family caregivers and providers (see sidebar, “Caregivers’ Health Often Suffers”). In 2005, Medicare spent $91 billion providing care and services to people with Alzheimer’s and dementia, a figure expected to increase to $160 billion by 2010.

“The bottom line [for health insurance plans] is to ensure that people with dementia and Alzheimer’s have reliable access to treatment and diagnosis,” says Richard D. Della Penna, M.D., medical director of Kaiser Permanente’s Aging Network and national elder care clinical lead. “We have developed care management and treatment guidelines. In the meantime, you have to create awareness that there is a problem that can be addressed. You won’t get anywhere until you do that.”

Over the past several years, health plans have started to develop programs for beneficiaries with Alzheimer’s that offer enhanced medical management to improve the quality of life for patients and their caregivers, Della Penna says.
Kaiser and Evercare (part of Ovations, a division of UnitedHealth Group, Minneapolis, a care coordination program for people who have long-term or advanced illnesses) are among the health plans that have developed cutting-edge care management systems to identify, diagnose, treat, and care for Alzheimer’s patients. “Caring for people with Alzheimer’s disease and other chronic illnesses places extraordinary demands on those living with the disease, their families, health care providers, and the nation’s health care system,” says John Mach, M.D., a geriatrician and Evercare’s chief executive officer.

Last October, Evercare launched the nation’s first Medicare Advantage Special Needs Plan (SNP) in Phoenix designed exclusively for people with Alzheimer’s and dementia. Many experts believe SNPs will steadily increase in the next few years as the Alzheimer’s population grows. Working with the Banner Alzheimer’s Institute to coordinate care in Maricopa County, Arizona, Evercare’s nurse care managers collaborate with Banner’s memory disorder specialists to diagnose and treat people with dementia and provide home care support. Evercare is expanding its SNPs for a variety of chronic conditions from seven states to 38 states.

“We have 2,000 nurses around the country who go into homes, do comprehensive assessments, and work with interdisciplinary teams to develop care plans,” Mach says. Bringing that model to Alzheimer’s patients seemed an excellent fit, he says. “We believe our care model will pay off in reduced co-morbidities and reduced hospitalizations for Alzheimer’s patients.”

Della Penna says there is a growing understanding among health plans that the cognitive deficits among Alzheimer’s patients preclude them from taking advantage of traditionally designed disease management programs. “This makes the medical cost for their other conditions much more expensive,” says Della Penna, who also is a national director with the Alzheimer’s Association. People with five or more chronic conditions make up 20 percent of Americans age 65 and older, yet they account for 68 percent of all Medicare spending, according to the Robert Wood Johnson Foundation.

“Alzheimer’s is a silent contributor to these other conditions,” Mach says. “We think we will see lower costs with our approach.” But improving the quality of life for Alzheimer’s patients and their caregivers is the key concern for insurers that are developing care management approaches, he notes. Improving quality includes developing evidence-based guidelines to diagnose dementia, increasing physician training using care managers, and a creating chronic disease model to coordinate care.

**Delivering Appropriate Care**

While some health insurance plans are in early stages of developing Alzheimer’s care programs, says Della Penna, virtually all plans offer disease management programs in a number of other chronic disease areas. Often these programs include Alzheimer’s care.
addition, SNPs offer opportunities to focus intensively on the needs of Alzheimer’s patients.

Several health plans have developed and increased access to multifaceted programs for Alzheimer’s patients, says Katie Maslow, associate director for quality care advocacy with the Alzheimer’s Association. These programs include:

- collaborating with local home and community care organizations to address such unmet needs as housekeeping, transportation, and home care;
- providing members, caregivers, and families with information on Alzheimer’s and dementia care approaches to reduce stress and depression; and
- integrating care management strategies to address other chronic conditions such as diabetes, heart disease, cancer, congestive heart failure, and stroke.

In 1995, Kaiser partnered with an Alzheimer’s Association chapter in Los Angeles to develop evidence-based guidelines for the diagnosis of dementia, including administration of the Folstein Mini Mental Status Exam and selected laboratory tests. Kaiser also has adopted post-diagnostic care guidelines, which include assessments for depression, activities of daily living, and wandering (becoming lost and forgetting how they got somewhere), and use of advance directives. The health plan educates primary care physicians and social workers about dementia care and works with members and their caregivers to increase referrals by physicians to community organizations.

“We found having a single point of contact in the delivery system is best,” Della Penna says. “If I am a primary care doctor and see someone who needs intervention, it is more efficient if I talk with somebody at the community agency with whom I have a relationship.”

As part of its chronic care model, Kaiser placed dementia care specialists in two of its hospitals in Los Angeles to help identify and diagnose Alzheimer’s patients and those with dementia and to work with local Alzheimer’s chapters to improve support and care coordination. In the 2004 American Journal of Managed Care, researchers showed that the program had positive results in caring for Alzheimer’s patients.

“We often see people with dementia end up at acute-care hospitals because they have not been properly diagnosed and treated or received sufficient after-care. Before we developed the model at the Los Angeles Medical Center we found most patients were diagnosed later in the disease,” Della Penna says. “We need improvement in recognizing Alzheimer’s symptoms, especially in earlier stages, and we are weakest in appropriate follow-up care and support. Nationally, most programs and practices are like that.”

Maslow says there are several Medicare Advantage plans that offer similar partnerships with local Alzheimer’s groups. For example, in a six-site demonstration project called Chronic Care Networks for Alzheimer’s Disease, association chapters partnered with the following
health organizations: Kaiser Permanente, San Francisco; PacifiCare Health System, Denver; UCare Minnesota, Minneapolis; Capital District Physician’s Health Plan, Albany, New York; Temple University Health System, Philadelphia; and VA Healthcare Upstate New York Network, one of the VA’s 21 integrated health systems.

Humana, Louisville, Kentucky; HIP of New York; and Sterling Life Insurance Company, Bellingham, Washington, are among the plans that offer expanded services for members with Alzheimer’s, company officials say.

Through its Medicare Advantage private fee-for-service plan, Sterling offers a voluntary care coordination program that provides telephone assistance from nurses to help members—including Alzheimer’s patients and their caregivers—obtain services and follow care guidelines, says spokeswoman Elizabeth Bardon. “We can help members review their medications to make sure everything is correct,” she says. “We can set up resources for day care, respite services [for family members], and transportation services.”

Since 2006, Humana has been developing a complex case management program to identify people with dementia and Alzheimer’s and to make sure they receive appropriate services, says Ken Hopper, M.D., chief medical officer with Corphealth, a Fort Worth, Texas-based subsidiary of Humana. Corphealth provides integrated medical-behavioral health care services.

“We work diligently to make sure what we do on the behavioral side works with the medical side,” says Hopper, a psychiatrist. “Many times Alzheimer’s patients have behavior issues that interfere with care, and many patients find themselves at an inpatient facility.”

Once Humana has identified a member with a complex condition or several chronic diseases, either a personal nurse or a case manager is assigned to discuss health issues with the member and caregiver. In a 2006 survey, 99 percent of participating members said the program had affected their thinking about health goals.

Nurses or case managers ask members a set of questions to find out whether they are experiencing some level of dementia. “We don’t do memory testing. We are just trying to understand the patient’s context and history,” Hopper says. However, if dementia indicators are present, Humana then refers the member to a specialist for diagnosis and treatment, which could include medication. Depending on the availability of services, Humana partners with local Alzheimer’s support groups to address members’ day-to-day needs.

“There are reports that patients are doing better with care management and the attention they are given,” he continues. “We are hoping to expand our services in this area.”

In 2001, HIP Health Plan of New York created a geriatric case management (GCM) program for its 130,000-member Medicare Advantage plan. The GCM is designed to help the frail
elderly who may have multiple chronic problems, impaired physical and cognitive functioning, or lack of social support, says Edward Anselm, M.D., HIP’s chief medical officer.

“Two-thirds of people with dementia have Alzheimer’s, but the problems are the same: issues related to self-care, compliance with medical regimes, and accidents,” Anselm explains. “This program is directed at assisting them all.”

An estimated 2 percent to 5 percent of HIP Medicare members are eligible for the GCM program. Candidates are selected by mining an administrative database for members who have frequent hospitalizations or emergency room visits or use several medications that could cause adverse effects when taken in combination.

Upon discharge from the hospital, frail elderly members also are identified by a comprehensive patient assessment to ensure that they will be able to cope at home. “We have close collaboration with the family, physicians, and other caregivers,” he says. “We identify medical conditions, functional status, home living conditions, and who is involved in care. For each individual we create a treatment plan and coordinate family and caregivers with community resources to maximize contact with local doctors.”

A nurse or a social worker is assigned to each member who is enrolled in the program, providing phone consultation, care coordination with physicians, and assistance in locating community-based resources, including visiting nurses and caregiver support services.

“It is a broad range of behavioral and structural intervention to minimize the risk of medical complications that befall the frail elderly,” Anselm says.

HIP’s GCM has improved the quality of life for members and their caregivers and has reduced emergency room visits and hospitalizations, he continues. “We are getting tremendous customer satisfaction because we are able to make a big difference in the quality of their lives.” It is estimated that participants generated an annual net savings of $4,965 each when compared with members who declined to participate.

SNPs for Alzheimer’s Offer Innovative Approaches

Created by Congress in 2003, SNPs are a special type of Medicare Advantage plan designed to allow organizations participating in the Medicare Advantage program to offer plans tailored to beneficiaries who need the most care—those with complex health care needs and chronic conditions. “There is a growing interest in special needs plans targeted for people with dementia that are allowed under Medicare Advantage,” Della Penna says. “The legislation is new and the programs are new, but there is a movement in that direction.”

However, statutory authority allowing SNPs expires at the end of 2009, and Congress is considering whether and how the SNP option should be extended. In 2008, there are 772
SNPs operating. A moratorium on new SNPs was enacted at the end of 2007 and there is a pending proposal that would establish more specific requirements for SNPs. A key question in the decision-making process about extending the SNP program is what special value they provide to their members.

Della Penna believes that SNPs for Alzheimer’s patients are important programs within the Medicare system because they define a model of care for evaluation, treatment, and aftercare. “These programs require basic levels of care” that not all patients currently receive, he says.

As the nation’s first SNP, the Evercare Health Plan for People with Alzheimer’s Disease and Related Dementia provides additional Medicare benefits. The cost for members is the standard monthly premium of $93.50 for Medicare Part B and $15.90 for prescription drug coverage, Mach says.

Benefits designed to meet Alzheimer’s patients’ unique needs include prescription drug coverage that promotes access to frequently used drugs; enrollment in the Alzheimer’s Association’s Safe Return program that helps reunite family members with a person with dementia who has wandered; and care manager coordination of Alzheimer’s disease education, training, and end-of-life planning services. Drugs specific to Alzheimer’s treatment, primarily Aricept, are included in the formulary, Mach says.

Evercare plans to enroll patients already diagnosed with Alzheimer’s—an estimated 47,000 people in Maricopa County alone, Mach says. This eligibility requirement allows the plan to make special programs available immediately that are appropriate to the beneficiaries’ condition and plan for addressing needs as the disease progresses. “We will offer state-of-the-art treatment and support and use our nurse care manager model to help patients manage chronic issues.”

Mach believes that bipartisan support for care coordination through SNPs is strong. “Some people feel that [SNP legislation] may need to be tightened up” to exclude certain plans designed to care for people with less disabling chronic conditions, he says. “Our hope is that Alzheimer’s SNPs will be recognized as essential” for an aging U.S. population.

Research Brings Hope

One of the most comprehensive studies on the quality of Alzheimer’s care and other chronic conditions for patients in medical groups was conducted by the RAND Corporation, Santa Monica, California, and published in the Annals of Internal Medicine. “The study found care of Alzheimer’s patients was really poor,” Della Penna says. The 2001 study, which used ACOVE (Assessing Care of Vulnerable Elders) quality indicators, found little attention has been paid to the quality of health care that vulnerable elders and other older adults receive.
For example, while people with heart failure received recommended evidence-based care 60 percent of the time, patients with dementia received evidence-based care only 9 percent of the time. The indicators used in the RAND study measure quality of care for 22 conditions that affect older adults, including dementia and Alzheimer’s. The indicators covered four areas of care—prevention, diagnosis, treatment, and follow-up.

Overall, only 30 percent of the quality indicators were met for age-related conditions that included falling and incontinence, the study found. The quality indicators set a minimal standard for acceptable care.

Some health plans use these indicators to assess whether providers are delivering care that meets minimum standards for quality. The recently updated ACOVE quality indicators are available in the October 2007 Journal of the American Geriatrics Society.

Proving that robust care management can improve Alzheimer’s patients’ quality of life and reduce costs is a major goal for health care organizations. One of the more promising care management research projects currently is under way at four Veterans Affairs medical centers, Maslow says, and health plans may decide to adopt the care management component if it succeeds. While results are not expected until 2011, the VA is hoping that the care management intervention being tested will reduce hospital and urgent care services.

One of the problems with Alzheimer’s is that a diagnosis is not made until symptoms fully develop. This delay is thought to worsen conditions and make caregiving more difficult. And since many experts believe Alzheimer’s is under-diagnosed, the Alzheimer’s Foundation of America recommends widespread memory screening for elderly patients. However, the Alzheimer’s Association discourages any screening that doesn’t involve a doctor who can refer patients to specialists or other medical resources.

Della Penna and Mach believe early detection through memory screening can help patients and their families. “As a physician who took care of Alzheimer’s patients for 10 years, I am in favor of screening,” Mach says, adding: “I am not sure exactly who should be screened. My opinion is that it might be justifiable for people over 75 knowing that age isn’t a perfect indicator, but it is a factor for increased risk for these patients.”

Maslow, however, says the Alzheimer’s Association is concerned that patients who are screened outside a medical setting may not receive accurate results and may therefore not seek needed medical evaluation.

“People who do not have Alzheimer’s or dementia but have limited education or speak English as a second language often score poorly on screening tests and may be told that they probably have Alzheimer’s or another dementia even though they really do not,” Maslow says. In this case, “If these people seek a medical evaluation, they will probably be correctly diagnosed, but they and their families will have experienced unnecessary anxiety,
and the health plan will have incurred unnecessary costs.” In 2003, the U.S. Preventive Services Task Force determined that there isn’t enough evidence to support or oppose routine screening. The USPSTF recommendation cites the American Medical Association and the American Academy of Family Physicians, which recommend that physicians be alert for cognitive and functional decline in elderly patients for recognition of dementia in its early stages.

Says Hopper, “I am in the middle on this issue. Screening has its advantages. You can intervene more quickly with cases. The downside is screening can go down the road where there is not enough clinical support [for patients once they are diagnosed].”

But an early-stage diagnosis allows people to make plans, obtain support, begin treatments, and make lifestyle changes before the disease worsens, Mach says. The five-minute memory screening consists of a series of questions to check memory and other intellectual functions and can indicate whether a complete medical evaluation would be beneficial.

Della Penna says if someone is not doing well with treatment, that person should be screened for Alzheimer’s and depression. “We need to diagnose people early and get them into treatment,” he says. The Food and Drug Administration has approved five drugs to slow the progression of Alzheimer’s disease by up to 12 months in some patients, but they are not cures, Della Penna says.

In addition to drug therapy, there is growing evidence that Alzheimer’s symptoms can be slowed by keeping physically and mentally fit. For example, in a 2006 study in the Annals of Internal Medicine, researchers found that adults 65 or older who exercised more than three times a week were less likely to develop dementia than those who exercised less. Researchers concluded that regular exercise can delay the onset of dementia and Alzheimer’s.

“There is emerging evidence that by keeping your brain active, maintaining your brain, using computer applications, for some people can reduce their brain age,” Della Penna says. “Physical exercise will help increase brain activity, and it also reduces lipids.”

Currently, there is no proven means of early detection of Alzheimer’s. However, there are several experimental therapies based on the amyloid hypothesis, which is that amyloid senile plaques accumulate in the cortical regions of the brain for those who are at risk for Alzheimer’s. Clinical trials are under way on human volunteers, according to the December 2006 New England Journal of Medicine. Researchers are also using magnetic resonance imaging (MRI) and positron-emission tomography (PET) scans to look for early brain changes and testing blood and spinal fluid for amyloid and other biomarkers to see if they can be used to confirm Alzheimer’s.

Researchers at the University of California compared PET scans and MRIs using special
tracking molecules. Of the 83 volunteers, 25 were classified as having Alzheimer’s, 28 as having mild cognitive impairment, and 30 as having no cognitive impairment.

Although researchers found some potential benefit to PET scanning, Medicare only pays for PET scanning in specified diagnostic circumstances because of questions about the necessity of using these scanning techniques to identify Alzheimer’s cases, Maslow says.

Della Penna and Mach agree that more studies need to be done to prove which approaches to prevention and treatment improve care and quality of life and reduce health care costs. In the meantime, having interdisciplinary teams deliver care can provide welcome relief to patients and caregivers living with Alzheimer’s.

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Caregivers’ Health Often Suffers

Caregivers for people with Alzheimer’s disease face grave, difficult, and stressful challenges as they balance their own needs with the increasing responsibilities of caring for a family member. Over the past 15 years, doctors and nurses who care for people with dementia have been advocating that additional resources be devoted not only to people with dementia and Alzheimer’s, but to family caregivers, say two leading geriatricians who hold leadership positions at health plans.

“We have seen families struggling with [care issues] for a long time,” says Richard D. Della Penna, M.D., national elder care clinical lead with Kaiser Permanente, Oakland, California. “They have received minimal longitudinal support and only episodic assistance for their roles as family caregivers.”

People with dementia often become confused and are prone to falling or wandering. They forget to take their medications, which exacerbates other medical problems and chronic conditions. Some develop behavioral problems and become aggressive or violent. Ultimately, some become incontinent, mute, and bedridden—totally dependent on others.

As Alzheimer’s continues to progress and destroy brain cells, patients increasingly depend on family members and others to carry out simple tasks like shopping and helping them get dressed. Caregivers often experience feelings of guilt, believing they are not doing enough to help, Della Penna says. They become fatigued from carrying out their new responsibilities and are prone to a variety of medical problems themselves, including depression and hypertension, he says.
“[Family caregivers’] role is everything,” says Elizabeth Bardon, a spokeswoman with Sterling Life Insurance Company, Bellingham, Washington. “They have to be able to help the family member get resources and be the ones to notice when things are not right with the family member.”

For example, the husband of a 75-year-old female, who developed Alzheimer’s with hallucinations after post-chemotherapy complications from breast cancer, faces enormous strain on a daily basis as he takes care of his wife, says B.J. Millan, a registered nurse and case manager with Sterling. “While the enrollee’s husband has some social supports, he is isolated in many ways,” says Millan, who coordinates care for the member. “Each time I talk to him I can hear an increasing level of fatigue in his voice. Our service gives him the opportunity to express his true feelings and problem-solve health issues.”

Millan says the patient, who is enrolled in one of Sterling’s Medicare Advantage private fee-for-service plans, is lucid at times and able to talk on the phone. “Through case management services we have assisted her in remaining in the home, provided emotional support to her husband, supported and explained physicians’ plans of care, and offered comfort measures and suggestions for dealing with states of dementia.”

**Helping Those Who Help**

As a geriatrician at the Minneapolis Veteran’s Administration Hospital, John Mach, M.D., now CEO of Evercare, based in Phoenix, saw how a team of internists, neurologists, social workers, and nurses provided high-quality care to Alzheimer’s patients and their families. “The team, unlike any other programs at the time, was built to care for people,” Mach says. “In the end, the patient and the caregiver had many more touch points to work with the patient on behavioral, wandering, mood, agitation, and medical issues.”

As part of its Medicare Advantage Special Needs Plan for Alzheimer’s patients in Phoenix, Evercare offers caregivers counseling to help them deal with the emotional and physical toll of having a loved one with Alzheimer’s and chronic dementia. Other services include bereavement counseling and emergency respite services to relieve family members or close friends who often need to deal with their own stress and health issues.

In the late 1980s, Kaiser created a geriatric services division in San Diego, staffed primarily by social workers, to act as a point of contact for frail elderly members and their caregivers, says Della Penna. “Any physician or nurse could refer patients to the program,” he says. “Half of those patients were demented. Many were over age 80 and had multiple conditions, including Alzheimer’s.”

In 2003, while 7 percent of Kaiser’s members age 65 or older were diagnosed with dementia, 28 percent of those 85 or older had dementia, Della Penna says. Nationally, an estimated 5.1 million people have Alzheimer’s, a figure most experts believe is a low
But the numbers of family caregivers may be even larger. Based on data from a national survey by the National Alliance for Caregiving and AARP, there were 10.4 million caregivers of people with Alzheimer’s or related dementia in 2003. Further analysis found that these caregivers provided an average of 16.6 hours of care per week.

According to the Alzheimer’s Association, more than 80 percent of caregivers report that they frequently experience high levels of stress, and nearly half say they suffer from depression. The Family Caregiver Alliance estimates that caregiving spouses between the ages of 66 and 96 who are experiencing mental or emotional strain have a 63 percent higher risk of dying than people the same age who are not caregivers. Sterling, Kaiser, Evercare, and many other health insurers offer respite services to family caregivers.

The following are warning signs of caregiver stress, according to the Alzheimer’s Association:

- anger
- anxiety
- denial
- depression
- exhaustion
- health problems
- irritability
- lack of concentration
- sleeplessness
- social withdrawal

Evercare is sponsoring the “Caregiver Notebook,” which is available through the Alzheimer’s Association and provides more information on family caregivers. Visit www.alz.org/living_with_alzheimers_caregiver_notebook.asp.