A ray of light in dementia’s long shadow

By Kay Lazar

Joe Foley, a retired college English professor, confided to his doctor that he was “leaking vocabulary,” struggling to find the right words. The diagnosis in April 2013: dementia.

If anyone was equipped to care for such a spouse it was Joe’s wife, Trisha, an unflappable Needham grandmother who worked as a nurse and has a PhD in counseling psychology. Still, the encroaching disease left her off-kilter.

Too often, families such as the Foleys have to wait until the ravages of Alzheimer’s and other forms of dementia do great damage before the health care system brings in its full firepower. But the Foleys were at the forefront of a growing effort by the health care industry to intervene sooner — an effort designed to help patients live healthier, crisis-free lives at home, ease stress on families, and potentially reduce costs for insurers.

More than 5 million Americans are living with Alzheimer’s disease, one of the most common forms of dementia, and that number is expected to triple by 2050, according to the Alzheimer’s Association. Mounting studies have found the person closest to an Alzheimer’s patient, typically an aging spouse, shoulders the heaviest burden of caring for the patient.

These caregivers often experience significant health problems themselves — depression, anxiety, stress, and isolation. Overwhelmed physicians who are tending to dementia patients often overlook the health and social service needs of the spouse, according to advocates.

The dementia care consultation program that helped the Foleys — a joint venture of the couple’s insurer, Tufts Health Plan, and the Alzheimer’s Association of Massachusetts and New Hampshire — was designed to ease that. Already, hundreds of families have been referred to the program by physicians.

Each patient, and the family member caring for the person, is matched with a social worker who helps them design a plan that includes regular, meaningful activities for the patient, and also assists in locating free or affordable community services and support groups. The aim is to help the patient live well at home for as long as possible, while securing regular respite time for the exhausted caregiver. All the information is shared with the patient’s physician.

The concept made sense to Thomas Croswell, chief executive of Tufts Health Plan. Croswell first got involved with the Alzheimer’s Association when his father, who died two years ago, was struggling with dementia.

Tufts does not yet have data to indicate the program has lowered costs overall, but there are positive signs it has benefited patients and reduced costly hospital visits, Croswell said.

“We know it’s helped avoid hospital readmissions,” Croswell said. “We know from anecdotal information that it’s valued
by families and physicians.”

Tufts is paying for the initiative. Croswell described the price as minimal, essentially the cost of two social worker salaries, and management to oversee the venture.

It was modeled on Partners in Dementia Care, which offered similar services to a group of veterans with dementia and their caregivers, then compared their outcomes after a year with a group that did not receive the services. Depression among caregivers who were offered the services was significantly lower than those who did not receive the help, according to a study led by David Bass, senior vice president for research and education at the Benjamin Rose Institute on Aging in Cleveland. The analysis was published in 2013 in the Journal of the American Geriatrics Society.

Bass, who has presided over eight similar studies during the past 20 years, said other researchers have also designed programs that show promising results for dementia patients and their families, but few have been implemented because of a lack of money.

“These positive things that can help with care, that have been proven in research they are effective, are not widely available because of limited reimbursement services,” Bass said.

In the Tufts program, a social worker is available by phone and e-mail, and regularly checks in with a caregiver if she hasn’t heard from the person in a while.

“She was a lifeline for me,” said Trisha Foley, 79. “So much of what happens during this process [of dementia] is unexpected.”

Elyse Rokos, the social worker, suggested that Foley think about enrolling her husband in an adult day health program a couple of days a week to offer him stimulating activities, while giving Trisha time to run errands. Rokos sent Foley a list of affordable programs near Needham. She coached her on questions to ask agencies that offer companions for dementia patients.

“Elyse was good at giving you a heads up, anticipating something before it happened,” Foley said. One especially helpful tip: attaching bells to doors so Trisha was alerted if Joe wandered out of the house.

A primary goal of the program is to reach families before caregivers burn out and their own health declines, Rokos said.

“Waiting for people to call in means we are reaching people when they are at the point of crisis, and are desperate for help,” Rokos said.

But it’s not just about the services that care consultants secure for families. It’s the emotional support they provide.

“Elyse was a good listener,” Foley said. “She is so sensitive to the way people need to hear things.”

Foley’s husband died in September. He was 84.

The dementia care consultation service started as an experiment four years ago and is now an established program offered free to families after a dementia diagnosis. It has helped as many as 400 families each year, according to James Wessler, president of the Alzheimer’s Association.

“If the family is better trained, and supported, and aware, it makes an enormous difference in what happens in the home,” Wessler said. “We are trying to make sure health care is delivered in a much more effective fashion, and improve the quality of life for patients and their families.”
The venture between Tufts and the Alzheimer’s Association has proved so popular that a similar collaboration should be up and running this fall at Beth Israel Deaconess Medical Center, a hospital spokeswoman said.

The association also recently launched a program with McLean Hospital. McLean’s memory clinic, which treats people with mental health issues who have developed dementia, pays for a staffer from the Alzheimer’s Association to meet with physicians, review cases, and reach out to families.

“Often, families are in denial, so they might not contact a care consultant at the Alzheimer’s Association on their own,” said Dr. Brent Forester, a geriatrician who runs the hospital’s memory clinic. “But if they are embedded in our clinic, families are much more likely to follow through.”