



SOCIETY OF ACTUARIES

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Care for the Caregivers

MEMORY CARE HOME SOLUTIONS TEAMS WITH WASHINGTON UNIVERSITY TO EVALUATE UNIQUE CAREGIVER INTERVENTION PROGRAM

by Lisa Baron

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A day does not go by when I'm not forced to advise a family about the difficult decision of placing a patient in a skilled care community. Daily, I make rounds and counsel children who don't know where to turn in an effort to effectively care for their parents at home. My staff is inundated with questions from overwhelmed caregivers about the disease of Alzheimer's and what assistance can they turn to in the community. As the caregiver experiences the impact of the stress on their system, often caregivers become my patient as well.

I've often wondered: Is there a social service out there to help these families at home deal with the 24/7 challenges of dementia care? There is. Memory Care Home Solutions (Memory Care) exists to extend and improve time at home for families who are caring for a loved one with dementia. Their in-home caregiver training and geriatric phone service assistance can help our patients, our staff and the individual struggling to retain abilities. Mostly, though, Memory Care helps stressed out and overwhelmed caregivers. There is no charge for families in need.

UNIQUE INTERVENTION

Family members who care for people with dementia need a wide range of support services to help them do the important work of caregiving at home. Memory Care, a St. Louis-based non-profit organization, provides comprehensive, in-home dementia caregiver training. Through the Customized Caregiver Training & In-home Consultation Program, a 12-month intervention combining personalized caregiver trainings and family conferences, Memory Care teaches families behavioral and environmental strategies

to increase quality of life at home. A strategy report sent to each family caregiver trained identifies all community resources available to assist the family. Washington University, Department of Psychology, is working in association with Memory Care tracking all outcomes related to reduction of caregiver stress and reduction of health care costs as a result of the Customized Caregiver Training & In-home Consultation Program.

"We want to keep the patients in a home environment as long as possible. The idea that an organization like Memory Care Home Solutions can expedite effective services for a patient with Alzheimer's disease and their caregiver is most exciting. It will provide a better environment for patients and also will save money because hospitalization and skilled nursing facilities are expensive and facilities are taxed in terms of the increasing number of patients. Lisa Baron [executive director] is an amazing young woman and she has organized this and is moving it along very nicely. It's a terrific organization," says Memory Care Advisory Council member Dr. William Peck, director of the Center for Health Policy at Washington University and former dean, Washington University, School of Medicine.

DEMOGRAPHICS

Alzheimer's disease and related dementias are progressive conditions that affect an estimated 4.5 million Americans (Alzheimer's Association, 2006). As these conditions advance, people afflicted with them need more and more direct supervision and care, as cognitive impairments worsen. The majority of care for people with dementia is provided by family members. Indeed, of 150,000 Missouri residents with Alzheimer's disease, 75 percent remain at home with family caregivers. Research suggests that the home will continue to be the primary site of dementia caregiving for years to come.

Most caregivers want to keep their family member with dementia at home for as long as

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possible.¹ Home-based care has numerous advantages, including the ready accessibility of caregivers who are familiar to the care recipient and a familiar physical environment. Moreover, from a health policy perspective, delaying institutionalization reduces overall medical costs.²

Unfortunately, while home-based care may be beneficial, it is associated with added responsibility and stress for untrained caregivers (usually family members).

CASE STUDY

When her husband Ed was diagnosed with Alzheimer's disease, Fern was immediately overwhelmed by feelings of shock, confusion and, above all, helplessness.

"My heart was pounding, and it was difficult to breathe," she remembers. "We left [the doctor's] office and sat in the waiting room, thinking that someone would come to tell us what to do next. But no one came."

Fern eventually sought help from Memory Care Home Solutions. Memory Care conducted an extensive evaluation of Fern and Ed's home environment and offered a comprehensive strategy for improving communication between the couple, reducing physical risks to Ed and improving Fern's confidence as a caregiver.

As Memory Care's executive director, Lisa Baron, explains, "The condition of the caregiver is often overlooked in cases of Alzheimer's or dementia. But as the population of the memory impaired grows, more and more people are left feeling overwhelmed and unprepared for the enormous demands of caring for their loved ones with dementia."

INTERVENTION

The active phase of the 12-month intervention begins with an initial home visit in month one, conducted by a Memory Care program coordinator. This visit lasts approximately two hours.

With a semi-structured interview, self-report questionnaires and a walk-through of the home, the program coordinator gathers extensive information about the caregiver and care recipient in their home environment. After the initial home visit, the program coordinator reviews the assessment information and develops an individualized, comprehensive strategy report that identifies the caregiver's strengths, outlines recommendations and strategies to address difficult issues and recommends appropriate community resources. This comprehensive, written report is mailed to the caregiver, and the program coordinator contacts social service agencies recommended to facilitate referrals. The program coordinator then follows up by phone with the caregiver to discuss the results of the assessment and the strategy report.

The overarching goals of the home visit and phone contacts are to:

1. provide education about dementia and cognitive impairments;
2. teach an environmental approach to managing behavioral problems;
3. assess the home environment and suggest modifications to optimize functioning;
4. practice effective communication skills;
5. instruct and implement ways to involve the person with dementia in self-care and other activities of daily living;
6. instruct the caregiver about how to employ assistive devices and where and how to purchase medical equipment; and
7. reduce caregiver stress.

Throughout this phase, the program coordinator is available by phone and e-mail if the caregiver has additional questions.

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Numerous studies have documented negative physical and psychosocial consequences of caregiving, including depression, reduced well-being and life-satisfaction, poor physical health and fatigue.

The maintenance phase of the intervention begins with a family care call placed by a Memory Care care coordinator in month three (three months after the initial home visit). In month six, the program coordinator conducts a follow-up home visit with all caregivers to gather comparison data to the baseline data originally collected. Family conference calls occur in three-month intervals after the second home visit through month 12 of the program tracking the following variables: caregiver self-efficacy, usage of health care services and costs they incur, caregiver and care recipient’s medication usage and costs incurred and home environment impairments.

WASHINGTON UNIVERSITY ASSOCIATION

Seeking an objective and clinically viable evaluation of its services to caregivers like Fern, Memory Care is currently collaborating with a research team from Washington University’s Department of Psychology. Headed by Assistant Professor of Psychology Dr. Brian Carpenter, the team is in the process of collecting and analyzing a wide range of data pertaining to caregivers’ financial expenses, emotional and psychological well-being and overall success in putting Memory Care’s home-centered strategies into practice. Dr. Carpenter’s team will publish the findings from its IRB-approved research in a study to be released in 2008.

“We’re enthusiastic about handling these aspects of the research,” says Dr. Carpenter. “The medical community stands to gain from an objective, empirically verified study on these specific services to caregivers. It’s not just Memory Care that will benefit from the study, but the increasing population of lay and professional caregivers as well.”

Along with the hoped-for endorsement of the medical and academic establishments will be the testimonials of caregivers like Fern. “I am now a

more confident caregiver and feel less stressed on a daily basis,” she shares. “It is comforting to know Memory Care cares for me, the caregiver, at this time of great need. This is simply priceless.”

Numerous studies have documented negative physical and psychosocial consequences of caregiving, including depression, reduced well-being and life-satisfaction, poor physical health and fatigue.^{3,4} Furthermore, caregivers who are overwhelmed and under-supported are likely to turn to nursing home placement at higher rates and earlier in the course of dementia.⁵

Your knowledge and referral to this program will assist your staff, your patients and the efficiency of health care systems in general. The society is supportive of cutting edge community resources for important health care issues including the burgeoning population of overwhelmed caregivers of those with dementia. Memory Care offers a cutting edge program which serves as a national model and one the society is proud to support. ■

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