



## Family Caregiver Health: What To Do When a Spouse or Child Needs Help

*Gary Epstein-Lubow, MD*

**Scenario; Scene One:** You are finishing the office visit, suggesting to your patient's wife that she schedule the next visit in four to six weeks. By then, the new memantine starter pack will be finishing. While walking near your patient toward the door, she says softly so only you can hear, "I don't know how much longer I can do all this." You know she's been stressed, you have heard about this from their daughter, but the only person in the family who is truly your patient just walked nonchalantly out of the room, unaware of his wife's distress.

**Family caregiving is common in the United States.** A caregiver is a person who provides unpaid assistance with daily activities to another adult. The specific assistance must be beyond the "normative" or "usual" responsibilities that one would undertake in a marriage or as a parent, grandparent, offspring or friend. There are about 44 million American caregivers,<sup>1</sup> 22% of whom care for a person who has **Alzheimer's disease (AD)** or "mental confusion".<sup>2</sup> Compared to family caregivers for patients with other diseases, those who care for a person with AD are twice as likely to be providing the highest level of home care (more than 40 hours of direct care each week), and are also more likely to be living with the person.<sup>2</sup>

**Caregiving is a public health priority.** Determining the cost of family caregiving is made difficult by methodological challenges; however, a recent study estimated household costs between \$5,500 - \$12,350/year and reduced work hours or job loss due to caregiving responsibilities for 34% of caregivers.<sup>3</sup> Caregiving can be more cumbersome for women, who serve as 50% of the workforce and also provide most home-based caregiving. Now, with the aging of the baby boomers, family caregiving will soon emerge into the public health spotlight. Population-based studies at the state level are being called for in order to identify the most-vulnerable caregivers and the interventions with the greatest evidence base of benefit.<sup>4</sup> This public health directive is in part driven by concerns about depression and other illnesses in caregivers.

**Caregiver burden and depression are serious concerns.** The typical dementia caregiver experiences a variety of mild to moderate depressive and anxious symptoms.<sup>5</sup> These symptoms may be described as "burden," a specific type of stress experienced by caregivers. Few longitudinal studies have been conducted regarding burden; however, it is likely that chronic burden increases the risk for subsequent depression.<sup>6</sup> Self-report, structured interview and longitudinal data show dementia caregivers

to be at significantly increased risk for depressive and anxious symptoms. In the general population, the estimated lifetime prevalence of major depression is 10-25% for women and 5-12% for men, and the rate of major or minor depression in late life is 11%; in contrast, the risk for depression in caregivers is about two to three times these rates. Ultimately, one-third of all dementia caregivers will experience a major depressive episode, and at least half of these caregivers will struggle with chronic symptoms. Symptoms may persist without clinical intervention because few caregivers seek treatment for themselves.<sup>7</sup>

**Caregivers are at risk for medical illness and death.** In 1999, Schulz and Beach reported a 63% higher risk in 4-year, all-cause mortality for stressed spousal elderly caregivers.<sup>8</sup> Those caregivers who reported "some" or "a lot" of strain were at increased risk of death, compared to non-caregiving controls. Additional studies have shown that caregivers report worse health than non-caregivers, and engage in fewer health-promoting behaviors. They get less rest, sleep and exercise, and have worse medication compliance compared to non-caregivers. In a recent review, caregiver depression and care-recipient behavior problems were the factors most consistently related to worse caregiver health, and this correlation was the strongest for dementia caregivers, the elderly, and men.<sup>9</sup> To add emphasis to these results, Christakis recently published data showing an increased death rate for spouses of hospitalized patients; spouses of individuals with dementia were the most at risk.<sup>10</sup>

**Psychosocial interventions produce improvements for dementia caregivers.** The literature regarding family caregiving began over 40 years ago. Educational programs, a variety of psychotherapies and social support decrease depression<sup>11</sup> and other psychological distress. The most successful programs are intensive, involve family members, are modified to caregivers' specific needs<sup>12</sup> and include a social support or combined social support and problem solving approach.<sup>13</sup> To determine the best manner for individualizing effective treatments for caregivers, Schulz and colleagues developed "Resources for Enhancing Alzheimer's Caregiver Health (REACH)" and REACH II. REACH introduced multiple interventions across several sites, and produced small to moderate effects in depressive symptoms and burden.<sup>5</sup> REACH II investigated the effects of a multi-component intervention tailored to individual caregivers in response to an interview-based risk assessment; results at six months showed significant improvement in quality of life and reduced prevalence of clinical depression.<sup>14</sup>

**Scenario; Scene Two:** You ask the wife of your patient if she has another minute to talk, as you look toward the chair where she had been sitting. While she returns to her seat, you escort your patient to the waiting room and invite your assistant: "See if he would like a drink of water, I'm chatting with his wife for a few minutes." You begin the next five minutes by telling the caregiver that you would like her to schedule a longer visit when her husband returns. Then, in the brief time you have, try to sort out: does she need a referral for depression, more information about what to expect with her husband's illnesses, increased help at home, a support group, or simply reassurance that even though things may seem quite wrong, she is doing everything just right?

**What resources are available for caregivers in Rhode Island?** Helping caregivers manage and find additional resources is oftentimes the bread-and-butter of what office staff, social work and nursing are doing on both ends of the 15-minute office visit. It can be helpful to have one key staff person in your office who keeps track of local agencies and can take time to call a caregiver at home as an established part of her/his office responsibilities. You will want this person to inform you if the caregiver seems excessively stressed, confused or depressed, so that you may consider making direct contact with one of the caregiver's clinicians, who then might pursue a mental health referral. If your practice only occasionally requires caregiving resources, you could begin by calling a friendly geriatrician's practice, a local memory clinic or a private neuropsychologist. The Rhode Island Chapter of the Alzheimer's Association is an excellent resource for caregivers regarding both urgent concerns and routine matters related to dementia care; they offer educational programs and individualized referrals, and they maintain databases of support groups and counseling resources. For critical situations, it may be reasonable to recommend an in-home assessment or treatment plan that can be developed by a visiting nurse agency or a private geriatric care manager. For eligible patients, caregivers may benefit greatly from comprehensive services available through Hospice and the **Program for All-Inclusive Care of the Elderly (PACE)**. Finally, several ongoing caregiver research studies may provide telephone-based or other support; regarding dementia, the Alzheimer's Association provides a quarterly post of active studies.

#### Where to Find Assistance for Caregivers

- Office Staff
- Social Worker
- Primary Care Clinician
- Individual Counselor and/or Psychiatry
- Support Group
- Education and the Alzheimer's Association
- Home Health Services and VNA
- Geriatric Care Manager
- PACE
- Hospice
- Research Studies

**Scenario; Scene Three:** You receive a thank you note from your patient's daughter. She writes to tell you that her father is about the same but her mother seems much better. They don't know how much longer Dad will be able to stay at home; but for now, with the increased help and services, things are okay. She signs it, "Thanks, for your time, and your compassion."

#### Resources:

Alzheimer's Association, Rhode Island Chapter (401) 421-0008 or (800) 272-3900, <http://www.alz-ri.org/caregiver.htm>  
National Alliance for Caregiving, <http://www.caregiving.org/>

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The author has no financial interests to disclose.

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