

Meeting the Needs of Persons with Alzheimer's or Other Dementia
When No Informal Support is Available

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Center for Advocacy for the Rights and Interests of the Elderly (CARIE)
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Background

The Center for Advocacy for the Rights and Interests of the Elderly (CARIE), coordinates the Dorothy S. Washburn Legislative Committee comprised of legal, health and human services professionals as well as older consumers who monitor legislative and regulatory developments at the local, state and national levels in an effort to promote the well being of frail older adults. The Committee is concerned about the issue of those with Alzheimer's disease and other dementia who do not have a caregiver or responsible party to help them. There have been problems with these older adults being prematurely admitted to nursing facilities or being denied in-home services because of concern about liability. The Committee wants to draw attention to this population to begin to address their needs. There should be a dialogue about how to best strike a balance between preserving autonomy and allowing consumers to take some risks versus ensuring safety through more protective measures. While there is an abundance of information about Alzheimer's disease and related dementia and support for caregivers, there is little, if any, information for those who do not have a caregiver or responsible party. There is enough anecdotal evidence to assume that not all older adults have family or close friends available to help.

It is clear that there is a growing population of individuals with Alzheimer's disease and other dementias that present numerous challenges to our health and long term care systems. The Alzheimer's Association issued a report that estimates that 5.3 million Americans have Alzheimer's disease and the health and long term care costs are almost triple those of other older Americans. The report estimates annual costs of at least \$33,007 for those with the disease compared to \$10,603 for other older adults. This cost does not include the estimated 12.5 billion hours of unpaid care provided by almost 11 million caregivers who are primarily family members.¹ It is imperative that caregivers be valued and supported in their vital role. Unfortunately, there are no statistics readily available about the number of people who have Alzheimer's disease or dementia and who live alone.

"A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Study Group,"² describes the devastating impact of Alzheimer's disease on individuals, families, and our nation, and offers strategies and solutions to address the problems. The co-chairs of the independent Alzheimer's Study Group include Former Speaker Newt Gingrich and Former Senator Bob Kerrey. Former Justice

¹ "2010 Alzheimer's Disease Facts and Figures" at http://www.alz.org/national/documents/report_alzfactsfigures2010.pdf

² "A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Study Group" at (http://www.alz.org/documents/national/report_ASG_alzplan.pdf)

Sandra Day O'Connor is among the members of the group. The report highlights that "Over the next 40 years, Alzheimer's disease related costs to Medicare and Medicaid alone are projected to total \$20 trillion in constant dollars, rising to over \$1 trillion per year by 2050." On March 25, 2009, the Senate Special Committee on Aging held a hearing, "The Way Forward: An Update from the Alzheimer's Study Group."³ At the hearing, Former Senator Bob Kerrey emphasized that the disease creates a tremendous dependency on caregivers whose needs must be addressed by policymakers. There was no discussion about those who do not have a caregiver.

The Council of State Governments has issued a brief, "Cognitive Impairment & Alzheimer's Disease,"⁴ that describes why state legislators should be concerned about Alzheimer's disease and what they can do. The brief also identifies several states that have developed Alzheimer's disease plans to help progress with policy solutions. Some states' Alzheimer's Associations have also created a state plan. However, we could not identify any mention of this segment of the Alzheimer's population in any plan.

CARIE's Dorothy S. Washburn Legislative Committee makes the following recommendations:

Recommendations

1. Implement an epidemiological study to identify the scope of the problem.
2. Implement research to help identify best practices for ways to ensure early diagnosis for those who live alone. Issues related to stigma and cultural differences should be addressed. Quality assessments should be readily available in all communities for consumers who are becoming concerned about symptoms.
3. Design and fund demonstration projects to identify best practices and practical, cost-effective models for service delivery. There should be a balance between consumers' safety and their need for autonomy. Different needs, preferences and values should be considered. Models should be tested among various cultural groups to identify potential variance with approaches. Identify benchmarks and performance measures that foster good outcomes.
4. Research, design and implement clinical tools to help assess the decision-making capacity of individuals and work to maximize autonomy and

³ "The Way Forward: An Update from the Alzheimer's Study Group" at http://aging.senate.gov/hearing_detail.cfm?id=310462&

⁴ "Cognitive Impairment & Alzheimer's Disease" at <http://www.healthystates.csg.org/NR/rdonlyres/265E9FFC-18C4-4757-9254-CB6AC771EA46/0/AlzheimersTPfinal.pdf>

ensure individuals are engaged and involved in making decisions to the greatest extent possible.

5. Identify and utilize an ethical framework for assessment, planning and service delivery to ensure autonomy to the best extent possible as well as cultural considerations.
6. Identify best practices for health care professionals, social workers, and paraprofessionals needed to work with this population including competencies and knowledge needed.
7. Create training programs and help implement best practices for public safety officials such as police and fire fighters, emergency management personnel, and postal workers to help them identify those in need as well as where to turn for further assistance. Information should include but not be limited to what to do for someone who is found wandering.
8. Develop strategies to prevent financial exploitation and premature guardianships for those in the early stages of Alzheimer's disease or other dementia. Ensure access to legal services.
9. Create, test, and implement model community educational programs to increase public awareness and decrease stigma.
10. Encourage a comprehensive national strategic plan as well as the inclusion of the needs of this population in state plans.

Please contact Kathy Cubit at CARIE at cubit@carie.org or 267-546-3438 for more information or to provide feedback.