Special Care Units for People With Alzheimer's and Other Dementias: Consumer Education, Research, Regulatory, and Reimbursement Issues

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Foreword

Several million Americans have Alzheimer's disease or another disease or condition that causes dementia. As our population ages, the number of people with these devastating diseases and conditions will increase relentlessly. Families take care of individuals with dementia at home for as long as possible, but most individuals with dementia are likely to spend sometime in a nursing home in the often long course of their illness.

Until recently, little attention has been paid to the special needs of nursing home residents with dementia. In many nursing homes, they have received and continue to receive inappropriate care that exacerbates their cognitive impairments and behavioral symptoms and further reduces their quality of life. There has been a pervasive feeling that nothing positive can be done for nursing home residents with dementia. More often than nondemented residents, they have been overmedicated and physically restrained.

As awareness of Alzheimer's and other dementing diseases has increased, innovative approaches to caring for people with dementia have been developed. Some experts have recommended that nursing homes establish special units for their residents with dementia. OTA estimates that by 1991, 10 percent of all U.S. nursing homes had established at least one such unit.

Special care units promise to provide better care for individuals with dementia than these individuals would receive in nonspecialized nursing home units. On the other hand, existing special care units vary greatly, and many people believe that some special care units are established only for marketing purposes and actually provide nothing special for their residents.

This OTA report analyzes the available information about special care units for people with dementia. It discusses ways in which the Federal Government could encourage and support what is positive about special care units and at the same time protect vulnerable patients and their families from special care units that actually provide nothing special for their residents.

This is OTA's third report on Alzheimer's-related public policy issues. Two previous OTA reports, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias* and *Confused Minds, Burdened Families: Finding Help for People With Alzheimer's and Other Dementias*, have focused on biomedical and health services research and other components of the care needed by individuals with dementia. OTA hopes that these reports help to define and clarify the problems raised by Alzheimer's and other dementias and identify ways in which the Federal Government can assist in solving them.

OTA was aided in the preparation of this report by members and staff of the Alzheimer's Association, staff of the National Institute on Aging, special care unit researchers, State officials, and others. OTA wishes to thank all these individuals. OTA particularly wishes to thank Nancy Mace for her valuable contributions to this and OTA's two previous reports on Alzheimer's and other dementias. As with all OTA reports, the content of this report is the sole responsibility of the agency and does not necessarily reflect the views of these individuals or the members of the Technology Assessment Board.

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