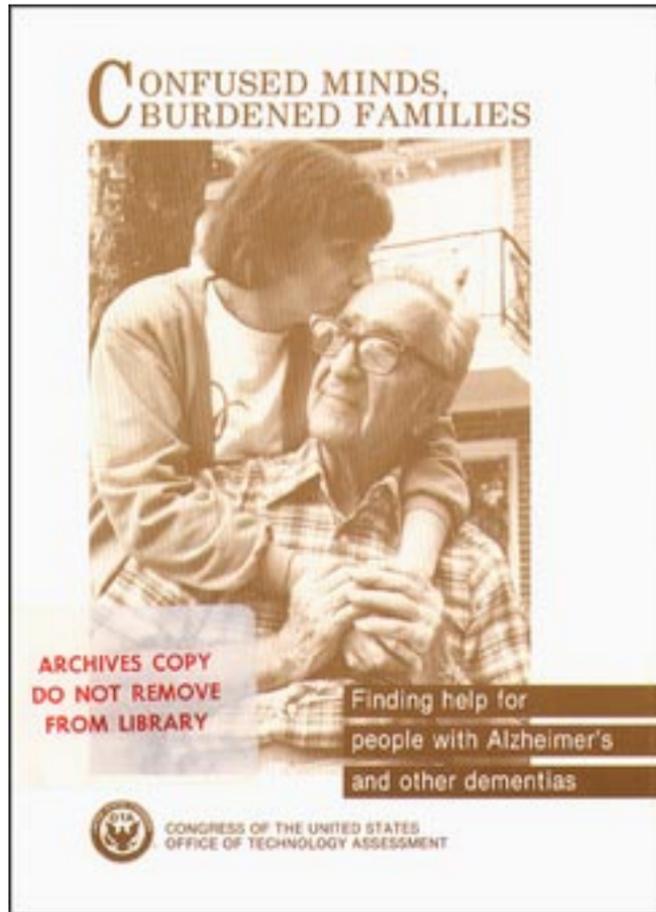


*Confused Minds, Burdened Families:
Finding Help for People With Alzheimer's
and Other Dementias*

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Foreword

Taking care of a person with Alzheimer's disease or another disease that causes dementia is a distressing process that may last for many years. For a variety of reasons discussed in this OTA report, families and others often have great difficulty locating and arranging the health care, long-term care, and other services they need to help them care for their relative or friend with dementia. People with dementia who live alone and have no family member, friend, or neighbor to help them are not able to locate or arrange services for themselves and often are not aware of their need for services. As a result, some people with dementia do not receive any services. Some receive inappropriate services, and some are connected-sooner or later-to an agency or individual that provides the kind of help they need.

Not all services that may be needed for a person with dementia are available. The lack of sufficient services for people with dementia is an important public policy issue that was discussed at length in OTA's 1987 report, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias*, and remains to be resolved. To plan realistically for the care of their relative or friend with dementia, however, families and others need to know not only what services are available but also what services are not available.

OTA estimates that there are now about 1.8 million people with *severe* dementia in the United States. The recently reported results of a study in East Boston suggest that there may be as many as 4 million people with Alzheimer's disease at all levels of severity. Due to the aging of the population, these numbers will increase dramatically in coming years.

This OTA report analyzes the problem of locating and arranging services for people with dementia, presents a framework for an effective system to connect them to appropriate services, and discusses congressional policy options for establishing such a system. One of the main policy issues is whether the system should serve people with dementia exclusively or serve people with other diseases and conditions as well. Some Alzheimer's advocates and others believe that only a system intended to serve people with dementia exclusively would be sufficiently responsive to their unique problems and needs, whereas others believe that a system intended to serve people with dementia and people with other diseases and conditions as well would be more effective than a dementia-specific system in connecting people with dementia to appropriate services.

In the course of this study, OTA has been impressed by the large number of agencies and individuals that are trying to provide appropriate services for people with dementia and to connect them to the kinds of services they need. To establish an effective system to connect people with dementia to services would require the coordination and consolidation of these agencies' and individuals' efforts and would undoubtedly engender some conflict and disagreement about which agency or individual should implement the system in a given State or community or at the national level. On the other hand, the lack of such a system means that the continuum of care these agencies and individuals are trying to create may not be accessible by the patients and families who need it most.

On behalf of OTA, I wish to thank the advisory panel, OTA's contractors, and the many other individuals who helped OTA in the preparation of this report. As with all OTA reports, the content of the report is the sole responsibility of OTA and may not reflect the views of those individuals.


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Finding Help for People With Alzheimer's & Other Dementias
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NOTE: OTA appreciates and is grateful for the valuable assistance and thoughtful critiques provided by the advisory panel members. The panel does **not**, however, necessarily approve, disapprove, or endorse **this** report. OTA assumes full responsibility for the report and the accuracy of its contents.

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