

Dementia Caregiving: Opportunities and Obstacles in Texas

Joint Interim Committee on Alzheimer's Disease
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What We Need Caregivers to Do

- Provide food, shelter, and safe living conditions for patients
- Learn effective means of caring for patients
- Find resources for emotional support
- Have positive, mutually rewarding relationships with patients
- Identify and utilize community resources
- Maintain their own health

Available Caregiver Supports and Services

- Educational materials, including on-line and print
- Educational meetings
- Support groups
- Management assistance by phone, email, home visits by community health workers
- Adult day care
- In-home respite care
- Overnight respite care
- Assisted living (residential vs. nursing home)
- Long-term care (memory unit vs. general)

Barriers to Caregiver Support

- Availability
 - Medical, day care, in-home care, long-term care
- Accessibility
 - Transportation and language
- Affordability
- Stigma
- Quality of care provided
- Computer/access to Internet

Caregiver Information Needs (Culturally Competent)

- Must be widely distributed in non-traditional ways, including barber shops, beauty shops, grocery stores.
- Must include:
 - Available community services
 - Available diagnostic and treatment facilities
 - Patient management strategies
 - Availability of support groups
 - Financial and end-of-life planning

Available Texas Resources

- Alzheimer's Associations
- Area Agencies on Aging
- Aging and Disability Resource Centers
- Texas Department of State Health Services
Alzheimer's Disease Program
 - Families experience great frustration in locating and accessing supportive community services, and even when resources are available, families do not know where to find the needed information and services.

The Facts

- Caregivers rarely abuse long-term care.
- Caregivers keep their loved ones at home as long as they are emotionally and physically able (an estimated 76% of people with Alzheimer's disease live at home).
- Caregivers have more health problems than others do at their age due to the physical and emotional demands of caregiving.
- Caregiving can have negative effects on employment, income and financial security.

Caregiver Burden, National

Alzheimer's Association 2011 Facts and Figures

State	# of Caregivers	Total Hours of Unpaid Care	Total Economic Value of Unpaid Care
California	1,459,978	1,662,623,044	\$19,835,092,909
Texas	1,213,767	1,383,237,356	\$16,490,091,652
Florida	960,037	1,093,290,130	\$13,042,957,247

Caregiver Burden in Texas

Alzheimer's Association 2011 Facts and Figures

Year	Number of Caregivers	Total Hours of Unpaid Care	Total Economic Value of Unpaid Care
2008	760,548	656,505,018	\$7,287,205,697
2009	852,820	971,191,823	\$11,168,708,965
2010	1,213,767	1,382,237,356	\$16,490,091,652

Estimating the Economic Value of Informal Caregiving*

- **Kaiser averages state minimum wage plus Medicaid pay rate of personal care (\$15/hr in 1999)**
- **AARP weighs state minimum wage, state home-health aide costs and private home health aide (\$10/hr in 1999)**
- **NY Office for Aging based on Medicaid payment of \$10/hr for 24 hr in-home care and \$15/hr for part-time home care in 1999**

*Report of NY Aging Services Network, 1999

Options to Save State Resources

- Long-term care is the greatest expense
- Perhaps equally, dying in hospital
- Alternative : Home care through the entire disease course with appropriate and needed support for patients and caregivers and terminal hospice care
- Needed: Devoted and supported caregivers and appropriate duration of care/ end of life planning for patients

Current Action Needed for Texas

- Consider funding the recommendations of the 2010-2015 Texas State Plan on Alzheimer's Disease
- Consider implementing the recommendations of the Texas Council on Alzheimer's Disease and Related Disorders 2010 Biennial Report
 - What message should Texas employ and what resources should be made available to change the continuum of care from reactive to proactive?
 - Texas can conserve scarce resources by building on existing delivery systems statewide.
 - The ultimate goal is to identify and combine public, private and charitable forces, and establish where possible a single point of contact to address caregiver needs.

Caregiver Support by Disease Stage

- Early
 - Emotional support
 - Financial planning
 - Tips on dealing with memory impairment
- Middle
 - Assistance with household chores such as cleaning and cooking
 - Patient supervision
 - Caregiver time off (respite)

Caregiver Support by Disease Stage

- Late stage
 - 24 hr patient supervision
 - Assistance with grooming, bathing, dressing, eating
 - Time off (respite)

Caregiver-related Resources

- **Alzheimer's Association Facts & Figures 2011** highlights statistics regarding care giving in the US and by state:
http://www.alz.org/alzheimers_disease_facts_and_figures.asp
- **Alzheimer's Association Dementia Care Practice Recommendations**
http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp
- **Caregiver Notebook** for purchase from the Alzheimer's Association; the Alzheimer's Association also has technology for caregivers that provides access to on-line information and support
http://www.alz.org/living_with_alzheimers_caring_for_alzheimers.asp
- **Texas State Plan on Alzheimer's Disease and Texas Council on Alzheimer's Disease and Related Disorders Biennial Report**
<http://www.dshs.state.tx.us/alzheimers/default.shtm>