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Introducing the Quality Care Campaign

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8.10.04

The Association is planning a new initiative to improve the quality of care provided to people with dementia in nursing homes and assisted living facilities nationwide. The Campaign for Quality in Residential Care is a partnership between the national office and the chapter network intended to ensure the provision of quality care to the ever-increasing number of residents with dementia in long-term care settings. With around half of long-term care residents having cognitive impairment, facilitating the success of this campaign is a top priority for the Association.

Next Steps

Over the next three weeks, you will receive and be asked to comment on the Dementia Care Practice Recommendations being developed as the foundation for the campaign's activities. Your input is an invaluable part of the development process as the Association seeks to improve dementia care. All comments and contributions are welcome, and may be made via e-mail and/or during one of four conference calls (to be announced) to discuss the recommendations.

Background

Historically, the Association has supported research, advocacy, staff training and consumer education in long-term care through numerous activities and programs, including such projects as Guidelines for Dignity, Key Elements of Dementia Care, Family Guide for Alzheimer's Care, representation on the United States Senate Special Committee Assisted Living Workgroup and advocacy for improved quality assurance in nursing homes and assisted living facilities, as well as numerous innovative chapter-offered trainings for long-term care staff.

The campaign is a new, evidence-based effort to continue the Association's traditional focus on improving care. Two research projects form the primary foundation of the campaign's knowledge base. The Association sponsored a team of researchers to identify indicators of quality dementia care through a multi-state study of nursing homes and assisted-living facilities. This research study was directly informed by a panel of experts from the chapter network* providing valuable ongoing consultation to the research team. The study's findings, which will be published in a special issue of Gerontologist, have helped identify important quality issues. The second research project, a comprehensive literature review that national staff conducted on dementia care interventions, has helped identify good

dementia care practices. The results of both studies are helping us establish concrete practice and policy recommendations for improving dementia care in residential settings.

The initial phase of the campaign will promote the Association's general philosophy of care, informed by person-centered approaches, and make specific practice recommendations in three care areas: pain management, food and fluid consumption and social engagement/activity involvement.

The campaign will operate at multiple levels:

- It involves collaboration with government, industry and professional groups to improve the care provided to people with dementia in long-term care facilities.
- It will build consensus and use national and state policy efforts as well as advocacy with industry and professional groups to establish a regulatory environment that will facilitate the local implementation of quality care programming, to empower consumers and engage Association chapters in the education and training of long-term care staff.
- It will provide evidence-based, educational programming for facility staff of all levels and is designed to complement existing curricula already in use throughout the chapter network.

Below is a graphical conceptualization of the campaign, as well as a description of the evidence base for the project. Over the next few months, you will receive regular updates about the progress of the campaign in building consensus, eliciting input from key stakeholders and the development of practice recommendations, advocacy and educational programming.

If you have questions, please contact the campaign co-coordinators: [Peter Reed](#), director, care services (312.335.5178), or [Jane Tilly](#), director, quality care advocacy (202.393.7737, ext. 224).

*Members of the chapter liaison panel established for the dementia care research project include Peggy Bargmann (Florida), Carolyn Cunningham (national board), Scott Gardner (Arizona), Becky Groff (Iowa), Jan McGillick (Missouri), Clarissa Rentz (Ohio), Linda Sabo (New York) and Jan Weaver (Texas).

Conceptual Model

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Evidence Base

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Model Legislation

ALZHEIMER SPECIAL CARE LEGISLATION

Title

Section 1. –This statute is entitled “The Alzheimer’s Special Care Disclosure Act.”

Preamble

Section 2. –The legislature finds and declares that:

- (a) certain nursing home and related facilities, residential care/assisted living facilities, adult congregate living facilities, home health agencies, adult day care centers, hospices, and adult foster homes are presently known to claim special care for persons who have Alzheimer’s disease;
- (b) it is in the public interest to provide for the protection of consumers regarding the accuracy and authenticity of such claims; and
- (c) the provisions of the Act are intended to require such facilities to disclose the reasons for those claims, require records of such disclosures to be kept, require the appropriate state licensing agency (ies) to examine the records, provide penalties, and provide an effective date.

Definitions

Section 3. –For the purposes of this Act, the meaning of the terms specified shall be as follows:

“Alzheimer’s Special Care Unit/Program” means any nursing facility, residential care/assisted living facility, adult congregate living facility, home health agency, adult day care center, hospice, or adult foster home that locks, secures, segregates, or provides a special program or special unit for residents with a diagnosis of probable Alzheimer’s or a related disorder, to prevent or limit access by a resident outside the designated or separated area; and that advertises or markets the facility as providing specialized Alzheimer/dementia care services.

Special care unit disclosure by facilities

Section 4. –Any facility which offers to provide or provides care for patients or residents with Alzheimer’s

COMMENTARY

Section 1. *The title of the Act should conform to state practice.*

Section 2. *The preamble establishes the rationale for providing consumer protection in SCUs.*

Section 3. *This section defines Special Care broadly to ensure all possible variations are appropriately covered by the Act. In terms of referring to your state’s individual special care options as either “Units” or “Programs” it is best to mirror the language that providers are currently using when marketing them.*

Section 4. *This is the heart of the Act. It is intended to protect the consumers of Special Care Unit/Program services*

disease or other dementia by means of an Alzheimer's special care unit shall be required to disclose the form of care or treatment provided, in addition to that care and treatment required by the rules and regulations for the licensing of nursing facilities. That disclosure shall be made to the licensing agency (ies) and to any person seeking placement in an Alzheimer's special care unit/program of a nursing facility.

The information disclosed shall explain the additional care provided in each of the following areas:

(1) *Philosophy*. The Alzheimer's special care unit's written statement of its overall philosophy and mission which reflects the needs of residents with dementia.

(2) *Pre-admission, admission, and discharge*. The process and criteria for placement, transfer or discharge from the unit.

(3) *Assessment, care planning, and implementation*. The process used for assessment and establishing the plan of care and its implementation, including the method by which the plan of care evolves and is responsive to changes in condition.

(4) *Staffing patterns and training ratios*. Staff training and continuing education practices.

(5) *Physical environment*. The physical environment and design features appropriate to support the functioning of cognitively impaired adult residents.

(6) *Residents' activities*. The frequency and types of resident activities.

(7) *Family role in care*. The involvement of families and family support programs.

(8) *Program costs*. The cost of care and any additional fees.

(b) The licensing agency shall develop a standard disclosure form and shall review the information provided on the disclosure form by the nursing facility to verify the accuracy of the information reported on it. Any significant changes in the information provided by the nursing facility will be reported to the licensing agency at the time the changes are made.

Effective Date

Section 5 – This Act shall take effect upon passage.

from becoming victims of false claims made by care facilities. Detailed in the Act are specific areas of disclosure that closely mirror those outlined by the Alzheimer's Association in its Guidelines for Dignity: Goals of Specialized Alzheimer/Dementia Care in Residential Settings.

This section gives the Act "teeth" by spelling out the requirement that the appropriate state regulatory/licensing agency be appraised of any claims made by facilities regarding their Special Care Units/Programs, and provides a record-keeping requirement to ensure that such claims will be verified by the agency that renews the facility's license.

Section 5. *This section sets an effective date for the requirements of the Act to begin to take effect.*

Talking Points

ALZHEIMER ADVOCATES CAN USE THE ATTACHED TALKING POINTS TO EDUCATE LAWMAKERS ON THE NEED FOR SPECIAL CARE UNIT DISCLOSURE LEGISLATION

- **The objective of improving nursing home care for individuals with dementia will be better served by initiatives, such as this legislation, that protect individuals with dementia and their families from facilities that fraudulently claim to provide special care.** It is estimated that about 50% of nursing home residents in the United States have dementia, according to national surveys. These individuals may receive inappropriate care that will result in excess disability and severely reduced quality of life. According to a study on special care units, just over 19% of all U.S. nursing homes have a Special Care Unit. These units may vary greatly in terms of the quantity and quality of specialized care.
- **Residential long term care for persons with Alzheimer's disease is different than the care required of a person with skilled nursing needs.** Appropriate Alzheimer's care requires a focus on the psychosocial needs of the individual and provides specific therapeutic activities designed to maximize the individual's remaining cognitive and physical abilities, and to manage difficult behaviors that are often symptoms of the disease.
- **Consumers need assurances as to what, if any, special care a facility provides in the special care unit.** Specialized Alzheimer Units have been created as one part of a method for managing the complex care associated with dementia in a number of nursing homes and other care facilities. In many states without special care unit disclosure laws, these facilities are free to market their services and advertise themselves as providers of "special care" without any requirement to demonstrate why or how they are "special."
- **Special Care Unit disclosure procedures will reduce the opportunity for misleading marketing and unsubstantiated claims regarding such care.** The [model legislation] requires providers to publicly state the characteristics of their special care services, and gives consumers an opportunity to compare programs among various facilities.
- **Special Care Unit disclosure laws require such facilities to provide a description of the additional care that distinguishes it as being especially applicable to or suitable for dementia or Alzheimer patients.** A 1993 study by the Alzheimer's Association found that in many instances there was nothing "special" about these

Units. Furthermore, a significant percentage of facilities did not advise family members of alternatives to nursing home placement, did not discuss how physicians and other staff were selected for the program, did not make efforts to adapt the environment to meet the patient's needs, or did not have the appropriate furnishings designed to meet the special needs of residents with Alzheimer's disease. However, as the result of special care unit legislation enacted since the study, facilities that choose to market or promote themselves as providing special care by means of a special care unit have been made more accountable for the services they provide. In some cases, disclosure is reviewed as part of the facility's license renewal.

- **Special care disclosure legislation builds on Key Elements of Dementia Care, which defines six areas that residential care facilities must address to provide quality care for residents with dementia.**
- **While the [model legislation] does not provide specific requirements for Special Care Units, it does require facilities to maintain the standards that they set for themselves, while still allowing for future innovation.**
- **People with cognitive impairments are especially vulnerable to acts of fraud or abuse, and therefore, need protections such as those provided by the [model legislation].**