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## **Comfort Care in Advanced Alzheimer's Disease**

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## Comfort Care in Advanced Alzheimer's Disease

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Currently, an estimated 35 million people representing 13% of the United States population are age 65 and older. This percentage is expected to increase as the baby boom generation ages. As our aging population grows, so too will the number of people affected by chronic disease. Of particular concern is Alzheimer's disease (AD), the most common form of dementia among people age 65 and older and, inevitably, a fatal disease. Since the prevalence of AD doubles every 5 years beyond age 65, it is envisioned that millions of Americans will be diagnosed with AD in the coming decades.<sup>1</sup> In this article, we describe how the care of people with Alzheimer's disease presents a particular challenge to quality care at the end of life and introduce a Comfort Care Protocol as one approach to improving this care.

The average time between diagnosis of AD and death is 10 years, with the end stage of the illness lasting as long as 2 to 3 years. During the terminal phase, patients become bedridden and can no longer eat, drink or communicate. Death does not result directly from the neurodegeneration itself, but as a consequence of secondary impairments such as immobility, nutritional deficits, and infections. In addition, most AD patients are elderly and have other comorbidities such as heart disease or diabetes, which can contribute to overall decline and eventual death.

AD places an enormous burden on family caregivers over many years. It is estimated that half of all people with AD receive care at home, whereas the remainder are cared for in long-term care settings and other institutions. As the disease progresses, family caregivers often have no choice but to place loved ones in nursing homes. Families that choose to continue providing care at home usually assume this responsibility with little or no professional help. Furthermore, hospice, which is available both at home and in the long-term setting, is underutilized for those with AD. The Medicare Hospice Benefit requires two physicians to determine the patient has a 6-month prognosis or less. This policy has been viewed as a major barrier to admission of dementia patients to hospice.

Since many AD patients will receive care at the end of their lives in nursing homes, the quality of that care is an important concern. Studies of death and dying in the nursing home setting have identified deficiencies in staff knowledge related to palliative care,<sup>2</sup> inadequate pain management,<sup>3</sup> and lack of family satisfaction about terminal care delivered in the nursing home.<sup>4</sup>

The growth of the nursing home population, documented deficiencies in the quality of care provided to dying patients in the nursing home setting, and barriers to accessing end-of-life care through hospice clearly point to the need for end-of-life care research and quality initiatives in this area. To this end, Friends Nursing Home at Chandler Hall in Newtown, PA, a 53-bed nursing home with JCAHO accreditation, recently developed and initiated a Comfort Care Protocol to help improve the quality of care at the end of life. Nursing home residents whose estimated life expectancy is one year or less as judged by their attending physician are eligible for the Comfort Care Protocol.

The Comfort Care Protocol includes: 1) a detailed description of palliative care tasks for nurses, nurses aides, physicians, social workers and recreational therapists focusing on patient comfort, respect for patient dignity and wishes, maximizing

function and providing families emotional support and support for decision-making; 2) symptom management algorithms for pain, dyspnea, depression and anxiety management; and 3) an educational initiative with monthly in-services for staff and families on topics related to palliative care. Outcomes will be measured using a family satisfaction tool, a survey for staff satisfaction, and quality indicators related to pain and symptom management and communicating goals of care.

It is our hope that a structured Comfort Care Protocol will improve outcomes and become a standard approach to the care of dementia patients in other long-term care settings throughout the Jefferson Health System. We look forward to sharing the results of this project in an upcoming issue of this newsletter. Please address comments to Terri Maxwell at [terri.maxwell@mail.tju.edu](mailto:terri.maxwell@mail.tju.edu).

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