Improving the Quality of Life for Patients with Advanced Dementia

By Larry Beresford

An estimated five million Americans have dementing diseases, one million of them in advanced stages. Dementia refers to the progressive loss of memory and other cognitive functions, often but not always resulting from illnesses such as Alzheimer's disease.

NHPCO estimates that 10.3 percent of patients who died in 2006 while under hospice care had dementia as their primary diagnosis. This estimate is based on data submitted by 603 hospices in response to NHPCO's annual National Data Set survey.[1] An unknown number admitted with other diagnoses such as cancer, organ failure or general debility may have had dementia as a comorbidity or secondary diagnosis. What's more, the Centers for Medicare and Medicaid Services reports that 77,577 Medicare hospice patients were diagnosed with either Alzheimer's disease or Senile Dementia in 2005 (up from 31,797 in 2000). This growth in the number of Medicare hospice patients with the disease, in addition to the number of non-Medicare hospice patients, suggests a total annual hospice dementia caseload of 100,000.

Estimating life expectancy, recognizing when people with dementia have an appropriate prognosis for hospice care, and successfully obtaining coverage for their care from Medicare can pose significant challenges. NHPCO's Dementia Work Group is exploring these challenges, promoting additional prognostic research, and engaging in dialogue on coverage issues with Medicare fiscal intermediaries.

A new report from NHPCO suggests, however, that hospices can work within the current system to open doors for eligible patients and provide them with the palliative care services they need and deserve. The 27-page report, Caring for Persons with Alzheimer's and Other Dementias, is filled with concrete information on providing high-quality, evidence-based care and helping to maximize the quality of life of these patients and their families. It also features examples of hospices that are working effectively within existing eligibility guidelines. *(Members can download a copy of the report, free of charge. See page 46.)*

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March 2008

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Hospice Care Can Make a Difference

Patients with dementia who qualify for and are enrolled in hospice care are typically no longer able to express their end-of-life care preferences verbally. For such patients, it is important to look for guidance from advance directives or from their family's surrogate representations of their values, especially when it comes to clarifying important treatment decisions related to feeding tubes, antibiotics, rehospitalizations and the like.

But patients with advanced dementia may still express themselves through facial expressions, body language and how they react at meals or bathing times—challenging their caregivers to work with these demonstrated preferences rather than trying to force a meal or a bath on them using traditional language and interventions. Even if it takes a little longer, there are techniques that can be used to recognize, interpret and accommodate those behaviors in order to enhance, rather than detract from, the person's quality of life.

Most of all, the NHPCO report argues that hospices need to recognize that their skills—in symptom management, psychosocial and spiritual support, and bereavement counseling—can be extremely valuable to these patients and families. These individuals are in our communities today, eligible for hospice care and, in some cases, already on our caseloads.

Hospices are encouraged to seek out more information about the specific needs of these patients and provide targeted education to the staff members who care for them. In some cases, it may also be appropriate to consider the development of specialized services, teams, or programs for patients with advanced dementia.

For hospices, advanced dementia is the ultimate challenge, but also the ultimate opportunity to share the very best that is in our hearts and minds as caregivers. Strategies to promote and enhance quality of life—even when the patient is close to death—are the essential work of hospice teams. But we need to recognize that the life of a person with dementia has value and the treatment he/she receives can have significant impact on his/her life, for better or for worse.

Developing Specialized Dementia Services

Some leading hospices have developed specialized programs for dementia patients, using a variety of individualized responses appropriate to their particular settings, often in partnership with local chapters of the Alzheimer's Association. They have found tremendous responses to their specialized dementia programs in the elevated confidence and job satisfaction of their staff and volunteers, in the reactions of long-term care facilities, community physicians and other partners, from the public and, most importantly, from patients with advanced dementia and their families.

One of the more impressive examples comes from **Beacon Hospice**, headquartered in Boston, Massachusetts, with 20 offices across New England. In 2005, the organization began to assess what its teams were doing to enhance quality of life and preserve dignity and personhood for end-stage dementia patients. It made a major commitment to identifying and sharing best practices with its staff. A one-year exploration of these issues by a work group of about 20 members—representing different office locations and disciplines—led to the development of a menu of optimal, evidence-based interventions.

The program is called Deep Harbors, inspired by Beacon Hospice's lighthouse logo and the nautical theme in its publicity materials, reports CEO Betty Brennan, "We had the objective of developing a program that would create value for these patients, but also bring value to our own staff to feel more rewarded in providing the care. We recognized that it was difficult to measure the value of our services for these patients, but we went into this process saying there has to be something better."

Certain topics came up again and again in explorations of the medical literature and interviews with local experts in dementia and geriatrics. Eventually it was necessary to distill this broad dialogue down to a manageable menu of interventions, chosen based on their validation in the literature, feasibility of implementation by the hospice, and opportunities to involve all members of the hospice team. The work group's initial menu included four broad intervention areas aimed at enhancing quality of life for end-stage dementia patients and their families:

- Music therapy
- Therapeutic touch
- Advanced feeding techniques
- Pre-death bereavement support

A full-day training curriculum was developed to introduce the four intervention areas, along with a four-hour competency certification process. The hospice's expert consultants helped teach the curriculum, which was offered at multiple locations and times for the convenience of staff. Required certification for all agency staff (450 at the time of roll-out in January 2006), including office staff, has been monitored for compliance. New hires are oriented to the same content.

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Hospice of the Western Reserve (HWR) in Cleveland, Ohio, offers another example of an agency-wide response to advanced dementia. "In the Cleveland area, with its aging community, we were seeing our dementia numbers increase, particularly in our nursing home program," reports Bridget Montana, HWR's chief operating officer. "At the same time, our counselors were asking us how to make their visits with dementia patients richer and more engaging. They wanted our help, feeling that they weren't contributing much of value."

The agency convened a multi-disciplinary committee to study the issues of dementia care, and its members spent nine months attending professional conferences and reviewing hundreds of journal articles and other sources of expertise. As with Beacon Hospice, a few key themes emerged. These included:

- Understanding and assessing pain in people who can't communicate verbally;
- Distinguishing dementia from similar symptoms of delirium, which may be reversible;
- Finding ways to manage difficult behaviors by non-pharmacological means; and

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- Placing a greater emphasis on making every interaction with dementia patients deliberate and purposeful.

The planning group agreed that the human connection between hospice caregivers and patients with dementia is one of the most important aspects of the care provided. HWR's philosophy of person-centered care affirms and honors the value of the person, regardless of severity of cognitive impairment. It also recognizes the need for creativity, flexibility, and attention to the emotional needs of patients.

"Based on what we learned from the literature, we developed a teaching curriculum for person-centered hospice care, regardless of whether the patient can communicate verbally," Montana says. A basic four-hour course was offered to all clinical staff, with additional content for nurses. Patient care volunteers were trained in the basics of dementia and were given activity bags with sensory stimulation tools to help them in their work with patients. Expressive arts therapists offered in-services to hospice teams and shared a screening tool they developed to assist in determining when patients could benefit from art or music therapy.

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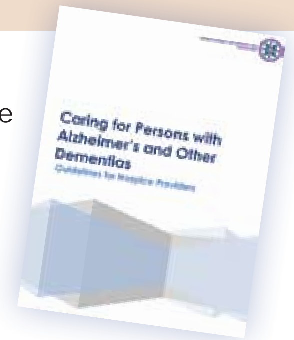
These are just two of the programs highlighted in the 27-page NHPCO report—Caring for Persons with Alzheimer's and Other Dementias. Members can download a copy of the report—free of charge. Visit nhpco.org/access and scroll to "Dementia."



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