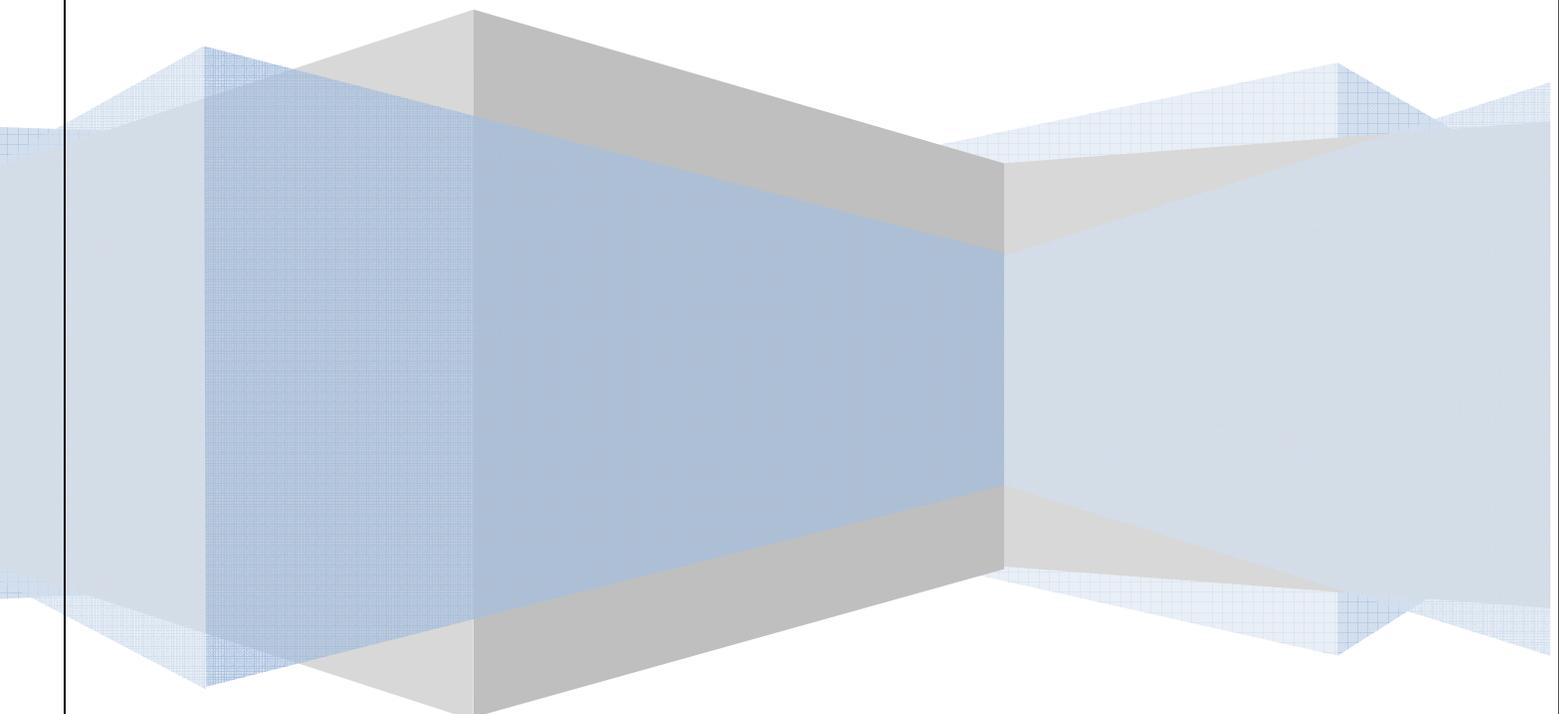




# Caring for Persons with Alzheimer's and Other Dementias

Guidelines for Hospice Providers





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## Opening Doors to Patients with Advanced Dementia

### *How hospices can enhance quality of life*

Richard Taylor was first diagnosed with an Alzheimer's type illness (dementia) seven years ago, a process that began with "nuisance" symptoms first noticed by Taylor and his family. He found himself becoming more easily disorganized, overwhelmed, moody and withdrawn. After being diagnosed with dementia, he had to give up his career as a psychologist working with suicidal teenagers and people who had experienced significant losses, but for several years he was able to continue teaching psychology with the help of assistants.

Today Taylor keeps busy, to the extent that his illness permits, with public speaking and advocacy for the needs and the rights of people with dementia. "When you have a cognitive disease, all of the time your brain is fighting the disease and trying to get reorganized, until it just gets overwhelmed." Dementia is a disease of the brain's "executive function," he says, but even more "it is a disease of your heart and mind".

Taylor challenges hospice professionals to become better informed about dementia and to honor the hospice



movement's philosophical commitment to promoting patient dignity and autonomy by listening to the wishes and care preferences of people with dementia for as long as they are able to express them. Competency is not all-or-nothing, he explains, even when the patient has a dementing disease that is destroying his or her cognitive abilities. For many, understanding comes and goes, and they may be competent to express preferences on some issues but not others.

"There are times now when I become bewildered or befuddled. I'm not aware of what's happening around me," Taylor says, even though he serves as a courageous and effective advocate for others like himself who face a future of progressively diminishing capacity. "People can have lucid moments, even in the later stages of Alzheimer's type illness. People can change their minds. Even in the advanced stages, if we take time to listen and explain things to them, they will be more responsive than we usually give them credit for." Most of all, Taylor says, caregivers need to keep driving back, as far as possible, the moment when the patient with dementia is no longer able to voice care preferences. "Anything less is giving up on their humanity."

### **The Role of Hospice in Dementia Care**

Patients with dementia who qualify for and are enrolled in hospice care typically are beyond the ability 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 understanding of their values, especially when it comes to clarifying important treatment decisions related to feeding tubes, antibiotics, re-hospitalizations. Many hospices are community advocates for and providers of education about the importance of advance care planning early in the course of the person's illness, so that values and preferences can be communicated to proxy decision-makers.

Patients with advanced dementia may still express themselves with 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 hospice caregivers can use to recognize, interpret and accommodate those behaviors in order to enhance, rather than detract from, the person's quality of life.

Quality of life is the cornerstone of hospice and palliative care, and strategies to promote and enhance quality of life—even when the patient is close to death—are the essential work of hospice teams. But it can be easy to lose sight of this goal when the patient is uncommunicative, unresponsive or unable to provide feedback that can be easily understood by the caregiver. Patients who cannot remember past experiences, have diminished cognitive skills, and have lost so many other traits that made them who they were as people sometimes are seen as “empty shells” or “already gone,” discouraging their caregivers' attempts at purposeful interactions.

In fact, one of the fundamental barriers to high-quality, end-stage dementia care is the failure of imagination—professional caregivers' inability to perceive that their interventions with patients matter and that how they treat patients has a significant impact on the patients' lives, for better or worse.

Hospice caregivers may also be prone to this lack of imagination, or awareness, but the best care for patients with advanced dementia calls on caregivers to actively improve the lives of their patients and support their families even when the losses appear to be profound. Trained in optimal dementia care techniques, motivated health professionals, paraprofessionals and volunteers are embracing the challenge of making a difference for patients with dementia and finding job satisfaction from the contributions they

### Key Clinical Issues in Dementia Care

A number of basic themes have emerged from the programs profiled in this report. Although discipline-specific interventions are explored elsewhere, the following are some key areas where improving caregiver skills and techniques will help to provide higher quality care for patients with advanced dementia:

- 1) **Decision making** about treatment options at the end of life should be promoted while the person with dementia still has capacity. As the disease progresses, advance care plans should be reassessed on a periodic basis and when the person's condition changes. This reassessment process should include the person with dementia for as long as the person can take part in the discussion and in concert with the caregiving family. Families not only need to be apprised of the changes in the person's condition and/or capacity, but also to be given support for their decisions and education about the benefits and burdens of care treatments including:
  - Nutrition and hydration
  - Hospitalizations
  - Use of antibiotics
  - CPR/Ventilation
- 2) **Communication** is essential to providing good dementia care. Assume the person can hear you. Use short sentences. Use direct eye contact, say the person's name frequently and tell them what is happening and what you are planning to do. Recognize that behavior and body language are communications, as well. Look for positive changes in their reactions to your interventions, acknowledge what you see the person doing and recognize that resistance, too, may be an attempt to communicate.
- 3) **Pain management.** Undiagnosed pain may be at the root of a variety of behaviors by non-verbal dementia patients. There are validated pain scales to assess pain in such patients, and dementia teams can become skilled at recognizing subtle signs and changes in behavior.
- 4) **Caregiver grief support.** Anticipatory grief may be an underlying issue for caregivers manifesting stress, depression or feelings of being overburdened. For many family caregivers, the losses they experience may be considered disenfranchised, because they are not acknowledged by society and thus not open to public mourning or social support. Assisting the family to identify and cope with their grief feelings prior to the patient's death can be a great source of comfort. Often this can be done on a group basis with educational presentations that allow family caregivers to come together and share their experiences. The Marwit-Meuser Caregiver Grief Inventory is used by some hospices to assess families' grief support needs.<sup>1</sup>
- 5) **Reminiscing and life stories.** Using the “Who Am I?” forms adopted by some hospices, caregivers can compile a good history of their patients with dementia from family and other sources. If the completed form is taped on the wall near the patient's bed, it can provide a starting point for everyone who visits the patient to encourage reminiscences. Note: it is important to follow HIPAA protocols in posting this information.

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make to their patients' lives.

They recognize, as Richard Taylor says, that lucid moments can happen even for people in the most advanced stages. They have established programs with names like Bright Eyes<sup>1</sup> or Deep Harbors (see below), which have as a goal generating some kind of response—a spark, a smile, a memory or a moment of lucidness in patients who others may view as empty shells. In doing so, they acknowledge the humanity of their patients to the very end of life, take responsibility for providing them with the best care possible, and see possibilities that exist for living and dying with dignity despite the ravages of a dementing illness. Such excellent care for people with dementia doesn't need to take a lot more time or expense than business as usual, so long as every interaction is planned and delivered with quality-of-life in mind.

For hospices, with our traditions, our philosophy, and our expressed goals of promoting death with dignity, 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. The purpose and focus of this report is how to make that a routine part of hospice care for the growing numbers of people with dementia enrolled in hospice care.

### What is Dementia?

As many as 5 million Americans today 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 an illness such as Alzheimer's disease. Alzheimer's is the most familiar form of dementia but others include vascular dementia and more rare forms such as Lewy body, Pick's disease, Parkinson's or Huntington's disease. Dementia is different than delirium and care must be taken to make the right diagnosis. People who have delirium may exhibit behaviors similar to those of people with dementia

### Key Clinical Issues in Dementia Care

Continued from page 4

- 6) **Minimizing the burdens of medical interventions** that don't offer long-term benefit should be considered but may cause suffering for demented patients who don't understand why they are being subjected to the invasive procedures and the disruption of their routines. This requires working with family members, and particularly the healthcare decision maker, to recognize the natural progression of the disease and to make treatment decisions based on what they believe their loved ones would have wanted. Advanced directives and previous advanced care planning conversations may be helpful, but so is encouraging the family to imagine that the patient could come back and stand at the foot of the bed viewing how they are today.
- 7) **Understanding Behavior.** A critical part of good dementia care is understanding the individual's behavior and what it is communicating. Care providers can address the underlying cause of behavior by connecting with the individual, tailoring the intervention according to the person's needs and following upon effectiveness of the intervention. It is not just about controlling the situation but making things better for the patient and family. Dementia experts say that there is usually a reason behind the patient's behavior—including striking out at others—even if that reason is not always obvious. Wandering behavior, for example, could be a manifestation of boredom, curiosity or restlessness. Key principles include anticipating basic needs and creating a familiar, friendly, comfortable living environment. Approach the patient in a non-threatening way. Introduce yourself and explain what you are going to do, even if they do not respond. Avoid direct confrontations. When working with aggression, don't argue; validate the person's feelings.
- 8) **Activities and sensory stimulation.** These include massage, music therapy, art therapy, other expressive therapies and a wide variety of simple interventions ranging from scented lotions to bubbles, balloons and balls, toy cars, stuffed animals and pet therapy. Some of the more complicated activity protocols, such as the Bright Eyes intervention cited above, utilize a specific sequence of senses to be stimulated, but basic sensory stimulations can be facilitated by supplying volunteers with an activities "grab bag" that could help stimulate a demented patient to show signs of awareness and enjoyment.

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<sup>1</sup> At the E.N. Rogers Memorial Veterans Affairs Medical Center in Bedford, MA. See: Trudeau SA. Bright Eyes: A structured sensory-stimulation intervention. In Volicer L, Bloom-Charette L, Eds. *Enhancing the Quality of Life in Advanced Dementia*. Philadelphia: Brunner-Routledge, 1999.

but they are different conditions and delirium may be reversible.

Depression may be a symptom or consequence of dementia but often is treatable.

More attention is given to care of people in earlier phases of dementing diseases and to the new pharmaceutical treatments that appear to delay the progression of dementia, including Cholinesterase inhibitors and N-methyl-D-aspartate (NMDA) receptor antagonists.<sup>2</sup> A recent report from the Alzheimer's Association, released in August of 2007 and endorsed by NHPCO, offers care practice recommendations for assisted living facilities and nursing homes focused on improving the end-of-life experience for people with Alzheimer's and other dementias.<sup>3</sup> The third installment in the Alzheimer's Association's Quality Care Campaign emphasizes the importance of advance care planning, provision of person-centered palliative care and dementia-specific training for long-term care workers. It also acknowledges the role of hospice care for some residents of long-term care facilities and the need for effective training, care coordination and communication between facility staff and the hospice.

NHPCO estimates that 10.3% of patients who died in 2006 while under hospice care had dementia as their primary diagnosis. This estimation is based on FY2006 data submitted by 603 hospices in response to NHPCO's annual National Data Set survey.<sup>4</sup> An unknown number admitted with other diagnoses such as cancer, organ failure or

general debility may have had dementia as a co-morbidity or secondary diagnosis. According to the Centers for Medicare and Medicaid Services, the dominant payer for hospice care, 77,577 Medicare hospice patients were diagnosed with either Alzheimer's disease or Senile Dementia in 2005, up from 31,797 in 2000. Alzheimer's disease has continuously been found to be one of the top ten Medicare hospice diagnosis codes from 1998 to 2005.<sup>5</sup> The steady

### Key Clinical Issues in Dementia Care

Continued from page 5

- 9) **Bathing, nutrition and physical care**—who is this stranger taking my clothes off? Bathing without a battle is a protocol developed by Joanne Rader and colleagues.<sup>2</sup> Consistent with the philosophy of care expressed throughout this report, if a patient with advanced dementia reacts negatively or resists a scheduled bath, it is incumbent upon the hospice team to be flexible and offer alternative solutions. This may mean trying again later, finding a source of distraction like singing together in the shower, offering a bed bath or whirlpool instead of a shower, using a towel warmer, and generally giving the patient options and choices. Weight loss, except at the end of life, may be related to giving patients foods they don't want to eat or pushing them to finish meals on the facility's schedule. Dementia-friendly foods are soft, sweet and cold and offered when the patient wants them—regardless of the hour. Popular choices include cookies, ice cream and blended fruit drinks. Near the end of life, people with dementia experience some natural wasting of their physical bodies due to decreased ability to manipulate and metabolize food.
- 10) **Spiritual care.** Rituals that patients are familiar with can be a great source of comfort and meaning, even for those with advanced dementia. Hospices need to recognize opportunities for creating spiritual connections, as well as the spiritual needs of persons with dementia to feel connected, to feel loved and to have hope. As part of getting a good life history, find out what was important, life-giving and meaningful to patients earlier in their lives and then offer those familiar spiritual or religious activities.

<sup>1</sup>Marwit SJ, Meuser TM. Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The Gerontologist* 42: 751-765, 2002.

<sup>2</sup>Barrick AL, Rader J, Hoeffler B, Sloane PD. *Bathing without a Battle: Personal Care of Individuals with Dementia*, New York: Springer Series on Geriatric Nursing, 2001, book and CD. See also University of North Carolina website: <http://www.bathingwithoutabattle.unc.edu/>.

<sup>2</sup> Fast Facts #5: Dementia Medications in Palliative Care. Morrison LJ, Liao S. See: <http://www.aahpm.org/cgi-bin/wkcgi/search?fastfact=1&search=1>.

<sup>3</sup> Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes—Phase Three: End-of-Life Care. Tilly J, Reed P, Gould E, Fok A, Eds. Chicago: Alzheimer's Association.

<sup>4</sup> National Hospice and Palliative Care Organization. (2007). Select results from the National Data Set. Data on file.

<sup>5</sup> Centers for Medicare and Medicaid Services. (2007). Medicare Hospice Data: 1998 – 2005. Available <http://www.cms.hhs.gov/ProspMedicareFeeSvcPmtGen/downloads/HospiceData1998-2005.pdf>. Accessed November 14, 2007.

growth in the number of Medicare hospice patients diagnosed with dementia and the addition of non-Medicare hospice patients (approximately 16% of hospice patients) suggests a total annual hospice dementia caseload closer to 100,000.

Estimating life expectancy, recognizing when people with dementia have an appropriate prognosis for hospice care, and successfully obtaining coverage from Medicare for their care can present significant challenges for hospices. Mitchell, et al., argue that the difficulties in accurately estimating life expectancy for persons with advanced dementia hinder the provision of appropriate palliative care in long-term care facilities.<sup>6</sup>

Some of the issues of eligibility for hospice care and new research on prognostication are outlined in the sidebars on pages 4-6 of this report. NHPCO's Dementia Workgroup is continuing to explore these issues, promoting additional research and engaging in ongoing dialogue with Medicare's fiscal intermediaries about eligibility issues. However, the challenges of eligibility should not be barriers to hospices providing quality care within the current system, opening doors for eligible patients and providing them with the palliative care services they deserve.

### **How to Open Hospice's Doors**

Many hospices today are working effectively with the existing eligibility guidelines to qualify and enroll patients with dementia. Recognizing that their skills in symptom management, psycho-social and spiritual support, and bereavement counseling can be extremely valuable to these patients and their families, hospices can use the Medicare guidelines to open doors to such care for all eligible patients. But only if they make it a priority—and only if they can imagine their ability to contribute significantly to these patients' quality of life.

The numbers certainly justify paying closer attention to dementia, and research published in the July 2007 issue of the *Journal of Pain and Symptom Management*<sup>7</sup> reinforces the value of hospice care for patients with dementia, based on evaluations of care by their families. "In spite of the challenge of caring for patients with dementia, hospice is indeed beneficial," concludes study co-author Dr. Stephen Connor, NHPCO's vice president of research. Families of patients with dementia actually rate the value of hospice care as highly as for patients with other diagnoses, and identify fewer unmet care needs for their loved ones.

Start by recognizing that these patients are in our communities today, eligible for hospice care and, in some cases, already on our caseloads, whether dementia is the admitting diagnosis or co-morbidity. Seek out more information about the specific needs of these patients and provide targeted education to the staff that cares 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.

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<sup>6</sup> Mitchell SL, Kiely DK, Homel MR, Park PS, Morris JN, Fries BE. Many nursing home residents dying with advanced dementia in U.S. *Archives of Internal Medicine* 164: 321-326, 2004.

<sup>7</sup> Mitchell SL, Kiely DK, Miller SC, Connor SR, Spence C, Teno JM. Hospice care for patients with dementia. *Journal of Pain and Symptom Management* 34(1): 7-16, 2007.



Some leading hospices have developed such specialized programs, 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 positive responses to their specialized dementia programs in the elevated confidence and job satisfaction of their staff and volunteers, from long-term care facilities, community physicians and other partners, and from the public. Most important is the response of the patient with advanced dementia, although this can be harder to evaluate.

### **Beacon Hospice Responds to Advanced Dementia**

What does it mean for a hospice to develop a specialized response to end-stage dementia and enhance quality of life for dementia patients? A variety of responses are possible, depending on the size of the agency, the population it serves and the resources it draws upon in identifying patients' needs and addressing them in a consistent, high-quality manner. One of the more impressive examples of a hospice agency's response to advanced dementia is **Beacon Hospice**, headquartered in Boston, MA, with twenty 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 then made a major commitment to identifying and sharing best practices with its staff. A one-year exploration of these issues led to the development of a menu of optimal, evidence-based interventions, accompanied by defined competencies and a process for certifying that staff meets those competencies. The program is called Deep Harbors, reflecting Beacon Hospice's lighthouse logo and the nautical theme in its publicity materials.

Beacon Hospice staff had been challenged by long-term care facilities to justify their value-added contribution for residents who had end-stage dementia and were unresponsive or unable to communicate verbally, 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."

A work group of about twenty members was formed, representing different office locations, different disciplines, staff experienced in dementia care and newer employees who could bring fresh perspectives to the issues. Under the leadership of corporate medical director Dr. Zoe Ann Lewis, this group met for a year to review a broad range of published medical and healthcare research and discuss issues uncovered in the literature. Certain topics came up again and again. At the same time, external explorations involved interviewing geriatricians and other dementia experts—both academic and clinical—in the local community, one-on-one and in focus groups. Some of these experts were brought in to speak to the internal work group, while topics and questions from the work group were cycled back to the experts.

All in all, Brennan says, it was a tremendous learning experience for the whole agency. 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. Some possible interventions were explored and set aside for one reason or another. 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 for families

These were all substantial interventions, chosen to raise the agency's service capacity, rather than just repackaging existing capacity, Brennan says. Music therapy, for example, was focused on people in the end-stages of dementia, based on the literature and input from academic schools of music, with interventions specific to each patient and his or her personal history.

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.

In general, the response from staff to this opportunity to participate in cutting-edge hospice care focused on quality of life for patients with advanced dementia has been highly enthusiastic. Home health aides, in particular, have been receptive to learning these techniques, and turnover among aides currently is less than five percent.

### **What are the Results?**

"We have had difficulty articulating quantifiable outcomes from Deep Harbors, although we have incredible anecdotes," Brennan says. Long-term care facilities have responded favorably, and community physicians also become enthusiastic when Beacon staff sits down with them and introduces the program.

"Recently, Dr. Ira Byock gave a presentation at the Alzheimer's Association conference. He explained what we're trying to determine when we assess our impact on the lives of patients with advanced dementia is whether we are creating *lucid moments*. Even though we see it every day with this program, how do you quantify it?" Brennan notes. Beacon has been working with hospice consultant Melanie Merriman of Touchstone Consulting in North Bay Village, FL, to develop outcome measures specific to Deep Harbors, starting with a family satisfaction survey for dementia patients on service longer than 30 days. The agency is continuing to work on developing ways to prove the value everyone believes it achieves.



“One of our nurses recently brought some non-toxic crayons and paper into the room of a dementia patient who hadn’t spoken in months,” Brennan relates. “This patient drew a heart on the paper and, with a lot of difficulty, printed her husband’s name. Art therapy is not even on our menu of interventions, but maybe we should go back and look at that, too.” Since the initial rollout, life review and tactile stimulation have been added as core interventions, with bathing alternatives next on the agenda. These additions are helping to bring the program into increasingly “deeper harbors,” she says.

### **Person-Centered Dementia Care**

**Hospice of the Western Reserve (HWR)** in Cleveland, OH, 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 broadly representative, 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, looking for ideas and techniques to help hospice clinicians do a better job of caring for people with advanced dementia. 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
- Placing a greater emphasis on making every interaction with dementia patients deliberate and purposeful.

Concerns about ensuring safety for patients residing in assisted living facilities dictated new management approaches deemphasizing the use of medications in behavior management. The agency is exploring non-pharmacological interventions with dementia patients as the focus for its participation in NHPCO’s national quality collaborative.

Overall, the project was a critical look at how the hospice could enhance its care for patients with advanced dementia and implement a comprehensive plan for achieving this goal. 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, and recognizes the need for creativity, flexibility, attention to emotional needs of patients, and seizing the opportunity for improving well-being in each patient encounter.

“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 given activity bags with tools for sensory stimulation to use with dementia 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. Hospice caregivers were taught to offer more concrete spiritual support and tactile interventions with their patients.

### **Getting to Know the Person**

A tool called “About You” elicits facts about who the patient was before getting sick—including hobbies, interests, family members, or favorite music and food. This information can be used to help spark a connection by revisiting memories during visits from hospice staff and volunteers. Understanding who the person is, how they have historically coped with change and stress, and what the family has found works or doesn't work in managing their care can be very helpful in targeting hospice staff's interventions. HWR adopted another tool, the Confusion Assessment Method (CAM) worksheet, to help identify when treatable delirium is present. A 16-page caregiver guide was developed as a resource for the families of HWR dementia patients.

Staff reacted very positively to the dementia curriculum, Montana reports. “People were genuinely excited. They could finally put a name to the frustration they had been experiencing, and now they had the tools to do something concrete about it. We also helped them to validate their contributions and to see the value-added, even when they think all they are offering is ‘presence.’” Adds HWR's Judy Bartel: “Our goal is to accept these patients—even if that acceptance occurs at the most primal level. If you get any kind of response back, that is a gift.”

Other issues arose from HWR's exploration of advanced dementia, such as the need to provide grief support to the families of dementia patients. Recognizing that grief may be intense before the patient dies, hospice bereavement coordinators have emphasized advance care planning, legacy work and use of the *ethical will*—which bequeaths a person's values, beliefs and reflections on life to those who come after.<sup>8</sup> Ethical wills come in many forms, including letters, artwork, poems, music or home videos. Family caregivers also need more grief intervention and support in the months before the patient's death, to help them normalize and cope with their feelings.

The hospice collaborated with the local Alzheimer's Association chapter on some of these programs and launched a media campaign to educate the public and families about dementia and the benefits of doing advance care planning while the patient is still able to participate.

As of October 1, 2004, 158 patients or 12 percent of the HWR's hospice census had a primary terminal diagnosis of dementia, while 134 had a secondary diagnosis of dementia, and an unknown number of hospice patients had a caregiver or significant other who had dementia. The hospice is measuring the quality of its specialized dementia

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<sup>8</sup> For more information, see <http://www.ethicalwill.com/>.

interventions on a number of fronts. For example, 48 percent of the hospice's patients with dementia now receive a volunteer for friendly visiting and companionship—a higher proportion than for non-dementia patients.

In measuring relevant questions from NHPCO's Family Evaluation of Hospice Care, HWR finds that its results are equivalent or even higher for dementia patients than for its overall patient population in terms of whether medicine was received for patient pain, whether support was provided to the family before and after the patient's death, and for the overall quality of care the patient received from hospice.

### **Other Dementia-Specific Programs**

Other hospices have also developed specific responses to end-stage dementia patients in their communities. **BJC Hospice** in St. Louis, MO, has explored dementia care needs under the leadership of medical director Dr. Poonam Jain, a gerontologist. "We developed a separate team focused on patients in long-term care facilities, representing the disciplines of nursing, home health aides, social work, chaplaincy, music therapy, massage therapy and volunteers," says hospice director Barbara Westland. "In one year, our long-term care facility-based census doubled to 70."

In working to develop a strategic approach to dementia care, this team spent a year exploring the issues and went on a staff retreat together. The agency developed performance guidelines and standards of care for dementia patients, with a routine order set specific to patients with a diagnosis of dementing disease and residing in a facility. "We're working with the local Alzheimer's Association chapter to develop a training module on dementia in long-term care. We're also holding a focus group with representatives of the long-term care education team and our team to explore the issues that make them uncomfortable and what additional information they would like to receive. This will help to set the parameters for our training," Westland notes.

"Our length of stay for these patients is short, but we're trying to make sure that when we get them on service, we're providing the best care possible, with interventions that are meaningful." The hospice employs two full-time music therapists and two full-time massage therapists, who are used for specific symptom management needs defined in the patient's plan of care, such as pain, anxiety or confusion.

"If there is going to be closer scrutiny on pain management in the nursing home, as we expect, we want to make sure we are doing everything at a high level," Westland says. The hospice is also emphasizing non-pharmaceutical interventions to help manage behavioral issues. Jain gives weekly presentations to staff on geriatric issues. One barrier that has emerged is the lack of understanding of optimal pain management techniques by the partnering nursing homes' staff.

**Hospice of Lancaster, PA**, after identifying that its patient care volunteers were feeling inadequate or even reluctant to visit patients with end-stage dementia, developed a four-hour training curriculum specifically for volunteers. The curriculum has been a hit, drawing interest from hospice professionals. A shortened version of the course was also offered at a recent Pennsylvania Hospice Network conference, says Leanne Porterfield, volunteer services manager.



A basic thrust of this education for volunteers is to validate what's happening with patients during the visit, striving to meet the patient's actual needs and make memories in the moment. "We wanted to make sure our volunteers understand that every visit to these patients is important, regardless of whether they are able to engage in reciprocal conversation," Porterfield explains. "We also spent a lot of time talking about centering yourself before going into the room, leaving personal issues or preconceived notions at the door."

Using interactive teaching methods and role-plays, the training shows volunteers how to project a calm, welcoming presence and tone of voice with patients, and how to observe and interpret their body language, gestures and facial expressions. "There's still a person inside the patient with a disease of dementia. If we are able to recognize it, we will focus less on negative 'behaviors,'" she adds.

Other elements of the four-hour training include information on cognitive impairments and dementing diseases, personal safety for the volunteer, activities to do when communication is difficult, and pain assessment scales. "Our job is to meet the needs of the patient and family while making sure the volunteer experience is a good one. That means providing them with skills to give patients with dementia specially focused attention and care." There has not been a quantitative evaluation of the volunteer training's impact on patient care, Porterfield says. "But we've already seen qualitative evidence in what the volunteers write in their visit notes, and in the length of their visits with dementia patients. Many also report that they find the visits more enjoyable."

**Hospice and Palliative Care of Louisville, KY**, which has offered an extensive public and professional education program through its Hospice Institute, has also partnered with local and state Alzheimer's Association chapters on educational programming related to dementia care. The agency is in the process of reworking all of its internal and external education offerings to make them more coordinated, consolidated and focused on targeted outcomes, with a singled branded image for the agency, says Hospice Institute director Joy Berger. The educational content is also being reviewed by people from different disciplines within the organization. Past educational programs have included:

- A four-week educational seminar for caregivers called "Planning for the Journey," co-sponsored by the Alzheimer's Association, with lots of practical information about caregiving as well as reinforcement of hospice's role;
- An ongoing professional continuing education partnership with the state Alzheimer's Association; and
- A series of dementia-focused seminars for long-term care facility staff, offering continuing education credits for nurses and social workers, with an emphasis on topics tied to the nursing home's training requirements as well as on eligibility and timing for hospice referrals.

The hospice emphasizes ways that music can elicit memories for its dementia patients. "There can be a moment, a window, an opening, a connection or some kind of physical response that music can facilitate," says Berger, who is

trained as a music therapist. "It has to be the music of the individual. But it can be such a positive experience, rather than just focusing on pathology." For its use of music, the hospice references books by Berger and by David Aldridge.<sup>9</sup>

For **Hospice of the Red River Valley**, Fargo, ND, the approach to addressing dementia care issues has been to focus on relationships with long-term care facilities, since that is where the majority of hospice-eligible patients with dementia live. The hospice has been seeing increasing numbers of patients with a primary diagnosis of either dementing disease or debility, says medical director Dr. John Thomas. "The majority of debility patients have significant dementia, even if they don't meet the guidelines for dementia. We don't see patients who have advanced dementia but are otherwise healthy. They all have co-morbidities."

HRRV established a dedicated long-term care team for its main Fargo office, although nurses in its other offices act as generalists, working with family practice physicians. As part of its relationship-building with long-term care facilities, the hospice aims to respond quickly to referrals, adapt its schedule to the needs of patients and the facility, and assist facilities in meeting their state surveys. It offers bereavement support to nursing home staff and access to psychiatric consultations for dementia patients. "We also work hard on our relationships with nursing home medical directors," Thomas says.

This focus on increasing skills in working with long-term care is helping to develop HRRV's "nursing home product line," he adds. "Our nurses see themselves as experts in symptom management, which is a big part of dementia care. They get good at recognizing subtle changes in their patients. They're able to raise questions about whether this individual's behavior is related to an undiagnosed pain problem. Nurses and social workers who have a lot of training and experience working with dementia patients are also able to help families anticipate what we see as a natural and obvious progression of the disease."

For Thomas, the real issue is access. "The number of dementia patients who die without the benefit of hospice services is pretty significant. We are challenged by the question of who is eligible to receive hospice care—not only for ourselves, but also to teach the facility's staff. But even before that is the need to demonstrate to the facility the value we add to the care of these patients—without making additional work for the facility. If they trust us and see the value of hospice care, they are more open to the conversation about who is appropriate."

Although there is no specific dementia program at HRRV, there is an emphasis on in-service education and new employee orientation on the topic. Thomas draws upon resources such as Ladislav Volicer's *End-of-Life Care for People with Dementia*, published by the Alzheimer's Association, for his in-service presentations. He believes that the agency's emphasis on long-term care facilities has also spilled over to home care, because HRRV has earned a reputation as an expert in dementia care.

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<sup>9</sup> Berger, J. *Music of the Soul: Composing Life out of Loss*. Brunner-Routledge, 2006. Aldridge, D. *Music Therapy in Dementia Care*. Jessica Kingsley Publishers, 2000.

“In our education we focus a lot on the Greatest Generation, which is the age of many of our dementia patients.” One of those patients, William “Bill” Hayes, a Fargo area man who died of dementia under the hospice’s care, was featured in a famous photograph from World War II with General Dwight Eisenhower. Corporal Hayes is pictured here with “23” on his chest, facing Eisenhower. His family has been willing to share his story publicly to help educate the community about dementia. Thomas often shares the Hayes photo and talks about the Greatest Generation in his public presentations in the community.



**Conclusion: Fulfilling a Mission, Enhancing Care**

Clearly, America’s hospices are learning to overcome the significant challenges of dementia care, and to develop the specialized programs, services and clinical competencies that enable them to make important contributions to the quality of life of patients with advanced dementing diseases and their families. In collaboration with local chapters of the Alzheimer’s Association and with partnering long-term care facilities, these hospices are honoring the lives patients with advanced dementia have lived—and are continuing to live.

Whether your organization develops a specialized response to dementia care, as the hospices profiled in this report have done, or simply uses resources and information highlighted in this publication to enhance the symptom management skills your staff brings to the care of dementia patients will depend in part on your community and its current level of unmet need. However, recognizing dementia care needs in your community and getting the word out about your ability to respond in a high-quality manner to those needs will go a long way toward fulfilling hospice’s mission in the community and enhancing the care of patients such as Bill Hayes and their families.

## Facts and Figures

Information provided here was compiled from Alzheimer's Association and NHPCO sources. All of the figures in this document are derived from *Alzheimer's Disease Facts and Figures, 2007* by the Alzheimer's Association unless otherwise stated.

### Dementia Defined

The general term "dementia" is used for Alzheimer's disease and other disorders that cause cognitive decline due to damage to brain cells. There is, however, a difference between dementia (the symptoms) and Alzheimer's (the disease). The following criteria must be met for the disease to be classified as dementia:

1. Memory impairment and one of more of the following cognitive disturbances:
  - a. Aphasia (language disturbance)
  - b. Apraxia (impaired ability to carry out motor activities despite intact motor function)
  - c. Agnosia (failure to recognize or identify objects despite intact sensory function)
  - d. Disturbance in the executive function(i.e., planning, organizing, sequencing, abstracting)
2. These symptoms cause significant impairment and represent a significant decline and the course of the disease is characterized by gradual onset and continuing cognitive decline that is not due to any other cause.  
(taken from the DSM-IV-TR, 2000)

Once it is determined that the person has dementia, the cause of the dementia is sought. Alzheimer's disease causes about 75% of all the dementias followed by vascular dementia, mixed dementia (Alzheimer's disease and vascular) and then a multitude of other diseases. In Alzheimer's type dementia, increasing numbers of nerve cells deteriorate and die. In this document, when the term dementia and Alzheimer's type dementia are used they refer to all types of dementia regardless of the cause of the dementia.

Studies have shown that a brain with advanced Alzheimer's type dementia has undergone severe shrinkage due to cell loss and widespread debris from dead and dying neurons. Historically different types of dementia have been associated with defined symptom patterns and distinct microscopic brain abnormalities, but increasing evidence suggests that these distinctions are artificial. Pathologies and symptoms often overlap in dementia, and they can be further complicated by coexisting health conditions.

### Symptoms of Alzheimer's Type Dementia

The effects of the disease can differ from person to person, but the most common symptom patterns begin with gradually worsening difficulty remembering new information. This is because disruption of brain cells usually begins in regions involved in forming new memories. As damage spreads, individuals experience other symptoms such as

confusion, disorientation, disorganized thinking, impaired judgment, and trouble expressing themselves. In advanced Alzheimer's, people need help with basic daily activities such as bathing, dressing, using the bathroom, and eating. Those in the final stages of the disease lose their ability to communicate, fail to recognize loved ones and become bed-bound. Alzheimer's disease is ultimately fatal.

### **Prevalence**

In 2007 it was estimated that about 5.1 million Americans have Alzheimer's disease. This includes 4.9 million people age 65 and older. It also includes at least 200,000 individuals younger than 65 with early-onset Alzheimer's. The Alzheimer's Association estimates there are approximately 500,000 Americans younger than 65 with Alzheimer's or another dementia. At a conservative estimate, at least 40-50% of them are likely to have Alzheimer's disease.

- 13% or 1 in 8 people age 65+ have Alzheimer's disease.
- Nearly half of people age 85+ have Alzheimer's disease.
- In 2004 Alzheimer's was the 5<sup>th</sup> leading cause of death for people age 65+
- In 2004 Alzheimer's was the 7<sup>th</sup> leading cause for people of all ages.

The number of new Alzheimer's cases has been on the rise in the recent years, due to the increasing number of people living into great age. In 1995 there were an estimated 377,000 new cases, and in 2000 that figure was 411,000. That figure is expected to increase to 454,000 new cases per year by 2010, 615,000 new cases a year by 2030 and as many as 959,000 new cases a year by 2050.

The number of people age 65 and over with Alzheimer's disease is estimated to be 7.7 million in 2030, a greater than 50% increase over the number currently affected.

### **Coexisting Medical Conditions**

People with dementia often have co-existing medical conditions. In 2000, 29% of dementia patients also had coronary heart disease (CHD), 28% had congestive heart failure (CHF), 23% diabetes, and 17% had chronic obstructive pulmonary disease (COPD). In fact, 95% of Medicare beneficiaries age 65 and older and with dementia have at least one other chronic condition.

Mortality rates for people with Alzheimer's type dementias have gone up by 33% from 2000 to 2004, while other leading causes of death have gone down (Heart disease: down 8%, breast cancer: down 2.6%, prostate cancer: down 6.3%, stroke: down 10.4%)

The most common causes for hospitalization for nursing home residents with Alzheimer's and other dementias are pneumonia and other infections.



### **Reporting Alzheimer's Deaths**

Deaths attributed to Alzheimer's disease have increased over the last 15 years. According to the Centers for Disease Control (CDC), Alzheimer's disease was listed as the "underlying cause of death" on 14,112 death certificates in 1991. In 2004 that figure was 65,829, showing an increase of 32.8%.

The number of deaths attributed to Alzheimer's has been on the rise while deaths attributed to heart disease, the number one cause of death, decreased by 8.0% from 2000 to 2004.

Because most individuals with Alzheimer's are age 65 and older, they also have other serious coexisting conditions associated with aging, and therefore physicians may tend to attribute death primarily to one of these other conditions even when Alzheimer's disease is present. In the large percentage of cases where the medical record fails to reflect an Alzheimer's diagnosis, the certifying physician may not be aware the individual had Alzheimer's disease.

One 2004 study by Larson and colleagues noted that people newly diagnosed with Alzheimer's survived about half as long as those of a similar age who did not have the disease. In this study, average survival time was four to six years after diagnosis, but survival can be as long as 20 years from first onset of symptoms.

The mechanism by which dementia leads to death may create ambiguity about the underlying cause. Severe dementia frequently causes such complications as immobility, swallowing disorders and malnutrition. These complications can significantly increase the risk of developing pneumonia, which has been found in several studies to be the most common identified cause of death among elderly persons with Alzheimer's disease and other dementias. One researcher described the situation as a "blurred distinction between death *with* dementia and death *from* dementia."

### **Medicare Coverage**

Medicare beneficiaries with Alzheimer's disease and other dementias use significantly more services and have significantly higher costs than other beneficiaries. Dementia complicates the care for coexisting conditions and therefore drives up costs. In 2000, the average Medicare cost for beneficiaries age 65+ without dementia was \$4,454, when the average cost for beneficiaries with Alzheimer's or other dementias averaged \$13,207. This figure suggests that dementia related expenses are three times higher per year than non-dementia related expenses.

### **Use of Services**

Although most families prefer to keep the person with Alzheimer's at home as long as possible, nearly everyone with the disease eventually needs more assistance than families and friends can provide, and moves into a long-term care setting.

70% of people with Alzheimer's and other dementias live at home, where they are cared for by family and friends. An estimated 70% of all nursing home residents have some degree of cognitive impairment.



### **Caregivers for People with Alzheimer's Type Dementia**

About 10 million Americans are caring for a person with Alzheimer's or another type of dementia. Because of the unique nature of dementia and its impact on the person's ability to do activities of daily living and because of the behavior changes that can occur, caregivers are stressed and at higher risk for becoming ill themselves. Over 40% of caregivers self report high levels of emotional stress. In a 2004 study, one in 5 caregivers for a person with Alzheimer's type dementia reported being in only "fair" or "poor" health themselves and 18% said that their caregiving made their health worse (Alzheimer's Association and National Alliance for Caregiving, 2004).

### **End-of-life care**

Hospice can provide palliative or comfort care that can help people who are terminally ill with Alzheimer's disease and other dementias. Medicare will cover hospice care if a physician certifies that a beneficiary is likely to die within six months. The Medicare hospice benefit, and hospice care in general, is underutilized. A 2005 survey by Harrison et al. estimated that only 43% of patients eligible for hospice ever receive services.

- NHPCO estimates that 10.3% of patients who died in 2006 while under hospice care had dementia as their primary diagnosis. This estimation is based on FY2006 data submitted by 603 hospices in response to NHPCO's annual National Data Set survey. (NHPCO NDS, 2007).
- A recent study investigated hospice referral in people age 65+ with advanced dementia who died within one year of admission to either a nursing home in Michigan or the state's publicly funded home care and community-based services. The results showed that only 5.7% of nursing home residents and 10.7% home care clients dying with advanced dementia were referred to hospice (Mitchell et al, 2004)
- One study reported that when persons with Alzheimer's and other dementias were hospitalized for pneumonia or hip fracture, half died within six months compared to cognitively intact patients, who were less likely to die after receiving the same treatments (Morrison and Siu, 2000).
- Morrison and Siu (2000) also indicated in this study that hospital patients with Alzheimer's disease often had untreated or undertreated pain.
- The number of hospice admissions for persons with dementia increased from 6.8% of all hospice admissions in 2001 to 9.8% of all hospice admissions in 2005 (NHPCO Facts and Figures, 2007).
- End of life care for people with dementia was sighted as being "extremely demanding of family caregivers" in a recent study, particularly during a "protracted and stressful" period preceding death. The stress was so great, many of the caregivers said that they expressed relief when death finally occurred (Schultz et al. 2003).



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## Disease-Specific Organizational Assessment<sup>10</sup>

*This checklist is to be used by providers to assess the ability of the organization in caring for patients with a variety of diagnoses. It is not all-inclusive and is intended as a general guideline to use in assessing the organization's ability to care for a wide variety of patients regardless of end-stage disease.*

### Patient & Family Centered Care

- Disease-specific care protocols reflect the principles of patient-family centered care by:
  - Recognizing the patient and family as the unit of care
  - Providing care that is responsive to the needs and exceeds the expectation of patients and families
  - Conveying respect and preserving the dignity of each patient and family
  - Acknowledging the individuality, culture, capacity, and abilities of each patient and family
  - Broadly defining family
  - Accepting the importance of families in the care and comfort of patients
  - Collaborating with and advocating for patients and families at all levels of care
  - Maintaining a safe and coordinated plan of care that includes the needs of the family
  - Developing a plan of care that includes bereavement needs, interventions, goals and outcomes for designated families and caregivers

### Ethical Behavior & Consumer Rights

- In the context of the primary diagnosis, staff ascertain and honor the wishes, preferences, concerns, priorities and values of patients and their families consistent with local laws, regulations, and the organization's values and policies
- Staff provide education to the patient/family about the disease process to ensure informed consent regarding treatment decisions and care planning
- The hospice advocates for the rights of patients and families and assumes responsibility for ethical decision making relative to disease-specific needs and the provision of hospice care overall

### Clinical Excellence & Safety

- Disease-specific care practices and protocols are based on clinical evidence
- Disease-specific care practices are systematically reviewed and updated
- The patient is assessed and disease-specific interventions provided as necessary to treat and prevent pain and symptoms using a holistic approach
- Disease-specific diagnostic services and therapies are provided when indicated for the management of symptoms according to the patient's plan of care

### Inclusion & Access

- The organization collaborates with disease-specific organizations and medical specialists to ensure timely access to care for eligible patients
- Disease-specific admission criteria are continuously reviewed to ensure they reflect best practices
- Inclusiveness is assured so that all individuals have access to hospice programs and services regardless of disease or other characteristics

### Organizational Excellence

- Organizational leaders ensure that services provided are appropriate to the needs of those they serve

<sup>10</sup> For a complete listing of standards relative to hospice care, please refer to *Standards of Practice for Hospice Programs* (2006). National Hospice and Palliative Care Organization [www.nhpco.org](http://www.nhpco.org)



- Marketing and related materials accurately and clearly describe the services available for all patients regardless of diagnosis/disease
- Organizational leaders build and sustain a culture of quality and accountability that values collaboration and ensures ethical business and clinical practices

### **Workforce Excellence**

- Interdisciplinary team members have disease-specific training that addresses the following needs:
  - Physical
  - Emotional
  - Spiritual
  - Grief and bereavement issues
- Interdisciplinary team members demonstrate disease-specific competence in:
  - Assessment of prognosis/terminality
  - Documentation of prognosis/terminality
  - Care planning for disease-specific issues
  - Care interventions for people with specific diseases
  - Evaluation of disease-specific care outcomes
- Organizational leaders assure continued education and ready access to information for related to disease-specific changes/updates

### **Standards**

- The organization adopts the NHPCO Standards of Practice for Hospice Programs (2006) and/or the National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care as the foundation for their organization

### **Compliance with Laws & Regulations**

- Organizational leaders maintain full compliance with all clinical standards of practice
- The organization uses accepted medical guidelines to determine whether a referred patient qualifies for hospice services

### **Stewardship & Accountability**

- Organizational leaders ensure availability of resources required by staff to provide services.
- Organizational leaders ensure effective resource management in the care of all patients regardless of diagnosis
- Protected health information is released only as directed by federal and state laws and regulations

### **Performance Measurement**

Using tools appropriate for special populations:

- The organization collects, analyzes, and actively uses performance measurement data to foster quality assessment and performance improvement in all areas of care and services
- The organization collects performance and outcome data related to patient care
- The organization participates in the collection of hospice comparison data as a means to determine areas for improvement



## Resources

### Web Sites

**Alzheimer's Association:** [www.alz.org](http://www.alz.org). The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research. Information, education and support are provided through these and a number of other means:

- A toll-free, [24/7 Helpline](http://www.alz.org) at 1.800.272.3900 for patients, families and professionals.
- Coast to coast [local chapters](http://www.alz.org), providing core services to families and professionals.
- [MedicAlert® + Alzheimer's Association Safe Return®](http://www.alz.org), a 24-hour nationwide emergency response service for individuals with Alzheimer's or related dementia that wander or who have a medical emergency.
- Annual [Dementia Care Conference](http://www.alz.org) and [International Conference on Alzheimer's Disease](http://www.alz.org).
- A peer-reviewed [research grants program](http://www.alz.org).
- [Advocates](http://www.alz.org) that educate Congress on critical Alzheimer policy issues and work to increase federal funding for research and care programs.
- Inside the Brain: An Interactive Tour at [http://www.alz.org/alzheimers\\_disease\\_4719.asp](http://www.alz.org/alzheimers_disease_4719.asp)
- CareSource – an online suite of services to help you find and plan for care: [http://www.alz.org/we\\_can\\_help\\_caresource.asp](http://www.alz.org/we_can_help_caresource.asp)
- Personal Facts and Insights: a format for understanding the individual with dementia at <http://www.alz.org/cafinder/support/documents/personalfacts.pdf>

**Alzheimer's Disease Education and Referral (ADEAR) Center:** <http://www.nia.nih.gov/alzheimers>. Information and resources from the National Institute on Aging (NIA). As a public, U.S. Government-funded resource, the ADEAR Center strives to be a current, comprehensive, unbiased source of information about Alzheimer's Disease. All information and materials about the search for causes, treatment, cures, and better diagnostic tools are carefully researched and thoroughly reviewed by NIA scientists and health communicators for accuracy and integrity.

**Caring Connections:** [www.caringinfo.org](http://www.caringinfo.org). This program of the National Hospice and Palliative Care Organization is a national consumer and community engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation. Caring Connections:

- Provides free resources and information to help people make decisions about end-of-life care and services before a crisis.
- Brings together community, state and national partners working to improve end-of-life care through a national campaign called It's About How You LIVE.

**National Hospice and Palliative Care Organization (NHPCO):** [www.nhpco.org/access](http://www.nhpco.org/access). The largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States, committed to improving end of life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.

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## Other Resources

### NHPCO Technical Assistance

- Standards of Practice  
<http://www.nhpc.org/i4a/pages/index.cfm?pageid=4900>
- Ethical Principles: Guidelines for Hospice and Palliative Care Clinical and Organizational Conduct  
<http://www.nhpc.org/i4a/pages/index.cfm?pageid=3273&openpage=3273>, under **Hospice Administration**.

### NHPCO InfoCenter: [www.nhpc.org/infocenter](http://www.nhpc.org/infocenter).

A member-only searchable database of journal articles, Web sites, books, conference papers and sessions, organizations, program assessment and improvement tools. Click on **Information Clearinghouse Database**, then **Special Focus Searches**. Under **Disease Specific Management**, click on **Alzheimer's Disease** for a listing of articles.



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Phoenix, AZ

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Fargo, ND

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Houston, TX

### **US Dept of Veterans Affairs Washington, DC**

Parag Dalsania, MD  
Director Geriatric Ambulatory  
Care Clinic,  
Geriatrics and Extended Care

## Participating Agencies

Betty Brennan, RN

Joanne Siefert  
Beacon Hospice  
Charlestown, MA

Poonam Jain, MD

Barbara Westland, BSN  
BJC Hospice  
St. Louis, MO

Joy Berger, DMA, BCC, MT-BC  
Hospice and Palliative Care of  
Louisville  
Louisville, KY

Bridget Montana, MBA

Judy Bartel, APRN  
Hospice of the Western Reserve  
Cleveland, OH

Leanne Porterfield

Hospice of Lancaster County  
Lancaster, PA

John Thomas, MD

Susan Fuglie  
Hospice of the Red River Valley  
Fargo, ND

## National Council of Hospice and Palliative Professionals

Richard Briggs, MA, PT

Enloe Hospice  
Chico, CA

Pat Gibbons, BSN, CHPN

Beacon Place/Hospice and  
Palliative Care of Greensboro  
Greensboro, NC

Patti Homan, PhD, LPC, FT

Hospice of Lancaster County  
Lancaster, PA

Carlyle Coash, BCC

Kaiser Permanente  
Martinez, CA

Phyllis Grauer, RPh, PharmD, CGP

Palliative Care Consulting Group  
Dublin, OH

Kathy Roble, MS

The Hospice of the Florida  
Suncoast  
Largo, FL

Cassandra Cotton, CNA

Nathan Adelson Hospice  
Las Vegas, NV

Joan K. Harrold, MD, MPH

Hospice of Lancaster County  
Lancaster, PA

Sherri Weisenfluh, MSW, LCSW

Hospice of the Bluegrass  
Lexington, KY



## **Acknowledgements, cont.**

### **National Hospice and Palliative Care Organization**

#### **Alexandria, VA**

Larry Beresford  
Healthcare Journalist, Consulting Writer

Kathy Brandt, MS  
Vice President, Professional Leadership,  
Consumer and Caregiver Services

Stephen Connor, PhD  
Vice President, Research and International  
Development

Helen Ennis  
Outreach Coordinator

Jennifer Kennedy, MA, BSN, CLNC  
Regulatory and Technical Assistance Specialist

Jonathan Keyserling, JD  
Vice President, Public Policy and General  
Counsel

John Mastrojohn III, RN, MSN, MBA  
Vice President, Quality and Palliative Care

Paula Palhus, BA  
Program Assistant Research

Judi Lund Person, MPH  
Vice President, Regulatory and State Leadership

Allison Petrilla, MPH  
Research Data Specialist

Jon Radulovic, MA  
Vice President, Communications

Coco Regas, MSW  
Consumer Programs and Services Director

Lin Noyes Simon, PhD, RN, CHPN  
Quality and Research Specialist

Carol Spence, RN, MS, CHPN  
Director of Research

Emil Zuberbueler, BS  
Director, Innovations