

# Palliative Care for Advanced Dementia

## *Adopting the Practice of Comfort*

by Natasha Bryant, Tena Alonzo and Carol O. Long

Unsatisfied with the state of the art in caring for people with advanced dementia, one continuing care retirement community partnered with a hospice provider and a foundation to develop a palliative care for advanced dementia program.

The resulting program, now in its fourth year, offers a person-directed approach that:

- Focuses on the person's comfort at all times
- Incorporates each person's life story into his or her care plan
- Creates a homelike environment individualized as much as possible for each resident
- Anticipates each person's needs rather than only responding to discomfort or negative behaviors
- Empowers frontline caregivers to do whatever is needed to make residents comfortable

Here is a look at the program's principles and practices, and the results of an evaluation.

According to an [Alzheimer's Association](#) 2010 report, Alzheimer's disease is the most common cause of dementia among older adults. It is the seventh leading cause of death and affects 5.3 million Americans, which includes 5.1 million adults 65 and older. The annual costs of hospitalization, physician services, formal and informal caregiving, medication and supplies for people with dementia are estimated at \$172 billion, including \$123 billion in Medicare and Medicaid costs. Unpaid care is provided by 10.9 million caregivers. Many elders with Alzheimer's will make nursing homes their final place of residence.

Providing the best possible quality of life and care for people with dementia can be a challenge for nursing homes. Persons with advanced dementia are most at risk due to the multiple losses they suffer with the progression of the disease. Sundowning, unexplained weight loss, multiple dementia-related behaviors, the lack of specific advance directives, the overuse of antipsychotics and restraints, and poor pain management are among the problems faced in dementia care.

Professional caregivers may not know state-of-the-art caregiving skills for these individuals, and family members may suffer in silence with tremendous grief as their loved ones deteriorate. Current caregiving practices do not



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Program participant Jessica Charlebois focuses on comfort with Health Care Center resident Lola Sholler.

meet the needs of people with advanced dementia.

We use the definition of palliative care offered by Dr. Christine Kovach at the University of Wisconsin-Milwaukee and her associates. They call it “comfort care that is holistic in nature and includes interventions which address symptom control, psychological needs of patients and families, quality of life, dignity, safety, respect for personhood, and an emphasis on the use of intact patient abilities and manipulation of the environment.” The goal is to relieve the pain, symptoms and stress of a serious illness and to improve the quality of life for the person. Palliative care can be delivered at the same time as treatment and it is not only for end-of-life care.

[Beatitudes Campus](#), a continuing care retirement community in Phoenix, Ariz., has developed a palliative care training program to improve the quality of care and quality of life for persons with dementia. The organization wanted to create a model program of advanced dementia care that could be replicated and sustained.

Beatitudes partnered with [Hospice of the Valley](#), a Phoenix-based not-for-profit hospice, and with funding from the [BHHS Legacy Foundation](#), created *Palliative Care for Advanced Dementia: A Model Teaching Unit Program* (PCAD). The program, now in its fourth year, emphasizes a person-directed approach to care and focuses on the comfort of the individual. Staff members learn best practices in dementia care and are empowered to endorse and enact the best care measures to meet the needs of the individual. Quality improvement measures are implemented to benchmark progress.

The goal is to educate staff and to change and embed best practices to improve the care for persons with dementia. The program focuses on professionals at all levels of the organization, including physicians, administrators, nurses, certified nursing assistants (CNAs), social workers, activity professionals, dietary and housekeeping staff. To date, program staff has trained 463 health care professionals from six long-term care communities and two assisted living organizations, representing over 1,165 individual learning encounters.

The key concepts of the program are the foundation for palliative care and include:

- Pursue comfort at all times for the person with dementia. Know how to make the person comfortable and communicate this to other team members caring for this individual.
- Know the person! Be knowledgeable about a person’s physical, psychological, social and spiritual history. Assure that the life story is incorporated into the care plan.

- Enact a person-directed approach to care that is individualized and meets the needs of the person and *not* staff routines. This means creating a homelike environment and supporting tactile, acoustic, olfactory, visual and thermal stimulations.
- Anticipate the person’s needs instead of waiting for the behavior to occur. The goal is to address the basic needs at all times. For example, offer foods and fluids before hunger and thirst develop. If a person has a history of pain, treat the pain before it becomes problematic.
- Staff members are the “voice” of the person with dementia; looking to resolve distress and assuring that comfort needs are met. Therefore, empower staff to do whatever makes the person with advanced dementia most comfortable.

The training program lasts approximately six months and includes additional education on pain management, stimulation of the senses training, and comfort-focused behavior management. One of the unique aspects of the program is peer training. Staff visits the Beatitudes for four-hour sessions to learn best practices and complete a set of competencies for their specific job descriptions. Each trainee is paired with a peer from the Beatitudes, across all disciplines and across all shifts, including caregivers and management. The focus of the peer experience is to demonstrate how the key concepts are manifested in the practice setting and how they support the overall comfort of the person with dementia. Nursing home medical directors also attend a session with the Hospice of the Valley medical team to understand medical management and advance directives at the end of life. In addition, the program includes a self-study component of materials that can be used for orientation of new staff and ongoing in-services.

### **Evaluation: How Well Does PCAD Work?**

Beatitudes staff not only created an innovative training program of best practices, but also sought to validate change and to determine the impact of the training program. Beatitudes’ research the first two years focused on specific resident outcomes and changes in the facility and staff. The findings showed:

- Positive improvement in weight management
- Appropriate medication use: decreased use of antipsychotic and sedative medications and increased use of pain and antidepressant medications
- Reduction in the cost of medications
- Reduction in restraints



Beatitudes Campus

Director of Research Tena Alonzo and Certified Nursing Assistant Victor Ortega are filmed on-site for a dementia training video.

- Reduction in hospitalization and emergency room visits
- Improvement in staff knowledge and positive perceptions of team building
- Belief among staff that they can have a positive impact on end-of-life care and palliative care

The evaluation, in the third and fourth years, focused on the dementia unit as a whole and not on individual residents.

Data was collected from the Beatitudes campus and one “nursing home in training” to compare the two organizations. A nursing home in training is one that is participating in the full six-month program. This community was comparable to Beatitudes. The evaluation assessed the quality of care for residents, staff knowledge and beliefs, and the cost of the program. Data for the quality of care study was collected at baseline, before the training program was implemented at the nursing home in training, and at six-month intervals to measure changes in practice, quality, and staff knowledge and beliefs. The findings showed positive changes in structure, process and outcomes elements that were evaluated. In addition, the quality measure yielded positive results but also identified areas that still needed work. Staff knowledge increased and beliefs about palliative care became more positive over time.

The [Institute for the Future of Aging Services](#) (IFAS) conducted a cost study to assess changes in costs at the nursing home in training attributable to the training program, and compared the findings to Beatitudes’ costs. The cost study questions captured the key elements in the training program that would be expected to show differences in practices and costs over the length of the project. Baseline data was collected before the training program. The training program was cost-effective; the nursing home in training and Beatitudes both realized savings. In addition, there were many valuable lessons learned from implementing this project.

### Results Leading to Greater Change

The training program gave rise to an opportunity to not only improve the individual caregiving experience of each person with dementia but also to enhance quality improvement across the organizations. Participating nursing homes found that their basic systems of care, such as scheduled dining or bathing times, were at odds with the needs of the most vulnerable

elders—people with advanced dementia. For instance, these nursing homes were concerned about encouraging rest periods if those rest periods coincided with meal times. Historically, most nursing homes have found it acceptable to wake a person to eat, which often creates a ripple effect of problems and discomfort. This practice is contrary to the PCAD program's support for individual preferences for waking, sleeping and eating on a schedule comfortable to residents.

Overwhelmingly, the nursing homes have found it easier to create comfort-focused changes in programs such as meal service if the changes are decided upon and implemented by an interdisciplinary team. Most were able to accomplish this through weekly or bimonthly meetings by considering the proposed recommendations for change first before embarking on quality improvement projects. Nursing homes found it easier to work on one or two areas of improvement at a time rather than everything at once. Although each organization approached its quality improvement plan differently, the time required to bring about change was consistently six months.

Some examples of quality improvement projects included restraint reduction, liberalizing diets, creating pain management teams and conducting pain rounds, and other creative endeavors. All found it useful to continuously reinforce what

the changes were and why they were needed. The reinforcement of change advanced the transition of the palliative care key concepts from the realm of training to actual practice.

Several nursing homes identified staff members who could assist peers in moving past the resistance expected with adopting the practice of comfort and with making the necessary changes in the quality improvement plan. These employees are commonly called "program champions." The frontline champions commonly did what managers struggled to do: convince peers that adopting new methods of caring for people with dementia was essential. Nursing home managers identified how important it was to prepare each program champion for any challenges, including overcoming peer resistance to change and modifying the quality improvement process.

Perhaps the most valuable lesson learned was the importance of celebrating quality improvement successes. The nursing homes that routinely acknowledged and celebrated the positive impact of their efforts reported increased staff satisfaction and increased feelings of accomplishment associated with caring for people with dementia. These organizations were able to change caregiving practices to the point that comfort was a part of every caregiving experience; it was ingrained into the thought processes of the caregivers and ulti-

mately became an expectation for all. Comments from CNAs included:

- “The palliative care training has given me the tools for a new way of thinking with residents at my facility. Thank you.”
- “We have a more consistent routine with the residents since our training; their routine is now based on what makes them comfortable and not what we want.”
- “The training taught me how important it really is to know your resident.”

Through staff training and empowerment, nursing homes were able to endorse individualized sleep/wake routines, opportunities to dine around the clock and highly personalized bathing schedules. In the end, the lesson most commonly echoed by those who participated in the PCAD program was that nothing is impossible and that people with dementia can live comfortably.

The impact of the program cannot be more clearly stated than by the comment of one family member, who wrote, “Who

do we need to talk to so we can make sure that every health care worker gets the palliative care training? You gave us our mother back; how can we ever thank you enough?” Another wrote, “This is most comfortable my wife has been in five years! The staff has made the difference.”

The PCAD training program provided information on “best practices” in dementia care for those in the moderate to advanced stage of the illness. Adopting a practice of comfort for persons with dementia can be achieved through specialized training and support for nursing homes. The provider organizations achieved cost-savings and positive changes in care trends and staff knowledge.

You can access more information about PCAD at the [Beatitudes Campus Web site](#).<sup>17</sup>

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