

2015

Bringing Comfort to People with Advanced Dementia

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Recommended Citation

Wyatt, A. (2015). Bringing Comfort to People with Advanced Dementia. *Age in Action*, 30(3), 1-5.

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Case Study

Bringing Comfort to People with Advanced Dementia

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Educational Objectives

1. Explain the purpose of looking at palliative care through a dementia lens.
2. Define dementia-capable palliative care.
3. Identify and provide examples of specific care practices that can bring comfort to people with advanced dementia.
4. Describe the process that staff use in identifying what brings comfort to individual residents.

Background

In 2012, the Alzheimer's Association, New York City Chapter, undertook a special project focused on palliative care for people with advanced dementia, based on the groundbreaking work at Beatitudes Campus, Phoenix, Arizona, which has invested considerable research

and training into expanding knowledge and practice in residentially-based care for people with advanced dementia.

The Beatitudes Campus of Care, founded in 1962 in Phoenix, now consists of a nursing home, assisted living units, and independent apartment units, as well as a home care program. More than a decade ago, staff members at Beatitudes began to focus more intensively on the care they provided to residents with dementia living in their nursing home. Using a comfort approach and working with their partner, Hospice of the Valley, they have identified a number of interventions specifically for people with advanced dementia living in residential settings. All of these interventions are based on knowing as much as possible about the individual with dementia, with the added dimension that these residents cannot usually articulate their needs, but often express them in other ways. Beatitudes offers specific practice changes that address not the behaviors, but the needs underlying them.

What attracted the New York Chap-

ter to the work done by Beatitudes is the degree to which they have identified the organizational adaptations necessary to support improved care practices for people with advanced dementia. Results of their efforts include the following: 1) liberalized diets contributing to stable weights; 2) increased toileting for reduced incontinence; 3) elimination of physical restraints; 4) almost no anti-psychotic, anxiolytic, and sedative medications; 5) increase in pharmacologic and non-pharmacologic methods for treating pain; 6) decrease in total number of medications prescribed; 7) elimination of "sundowning" symptoms; 8) improved staff knowledge, beliefs, and attitudes about palliative and end-of-life care; 9) residents receiving active comfort and even enjoyment from meaningful engagement; 10) greater family engagement and satisfaction; and 11) much improved staff satisfaction with almost no turnover. In recognition of their work, in 2010 LeadingAge gave them the Excellence in Research and Education Award, and in 2013 they received the LeadingAge Public Trust Award. Beatitudes has now developed an accreditation

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program, *Comfort Matters*TM, which is intended to educate and set the standard for dementia-capable palliative care.

Our project consisted of working with three nursing homes to bring the Beatitudes model to New York City: Cobble Hill Health Center; Isabella Geriatric Center, and The New Jewish Home, Manhattan campus. Also included in the project were the three hospice programs involved with these homes: Calvary Hospice, Metropolitan Jewish Geriatric Services Hospice and Palliative Care Program, and Visiting Nurse Service Hospice. Over a 30-month process of education, piloting, and evaluation, these homes worked to implement the practice changes pioneered by Beatitudes. Our intent was to learn from the process and understand the obstacles, so that our experiences could assist other homes in implementing these practices.

Why Palliative Care?

The purpose of palliative care is the prevention and alleviation of pain and suffering. The earlier that palliative care is involved, the better, when someone has been diagnosed with an acute, chronic, and/or terminal illness. While other specialists are treating the disease(s), palliative care focuses on symptom management, helping to ease stress for the person and for the person's family, including symptoms such as depression, pain, anxiety, or difficulty sleeping or breathing. Some researchers (Temel, Greer, Muzikansky, et al., 2010) suggest that this additional level of support and attention to comfort and quality of life may even prolong life. Further,

a focus on personal priorities with regard to treatment and comfort can help clarify preferences for medical care directives as the disease progresses. This person-centered focus has been shown to reduce the need for crisis hospitalizations (Mitchell, Teno, Kiely, et al., 2009).

The Palliative Care Disconnect for People with Alzheimer's and Other Dementias

Alzheimer's is a progressive, terminal disease, with the average time between diagnosis and death being about eight to 10 years; but it is extremely variable and can last up to 20 years or more. Typically, about 40% of this time is spent in the advanced stages. Palliative care has the potential to offer more over a longer time period for people with dementia; however, unless there are specific modifications in how palliation is offered to people with dementia, there is a strong possibility that it will be ineffective. Far too often, palliation isn't even considered as an option for people with dementia.

As an individual's dementia advances, his or her actions, rather than words, are more likely to communicate distress. Unfortunately, all too often these behavioral expressions are not understood as distress; rather, they are often assumed to be the inevitable consequences of the dementia itself. Palliation cannot occur if the reason or triggers for distress are not known or understood. Anti-psychotic and anti-anxiety medications do not take away pain, nor do they comfort, if someone living with dementia is hungry, cold, too warm, tired, or frightened by noises or activity in their envi-

ronment. Indeed, the medications may mask the continuing discomfort.

Dementia-Capable Palliative Care

In order to respond to the specialized needs of people with advanced dementia, dementia-specific practices and tools are needed to evaluate and to respond appropriately to their needs. In particular, this means: 1) use of a behavior-based pain assessment tool; 2) use of round-the-clock rather than PRN orders for pain medications; 3) offering food in small, manageable amounts, especially finger food, throughout the day and evening; 4) essential flexibility for rising, eating, bedtime, and other routines; and 5) attention to the needs of the person with dementia for a delicate balance of stimulation and rest in the environment throughout the day.

Advance Directives

Dementia-capable care practices aren't the whole story. Significant decisions must be made regarding aggressive medical treatments, traditionally used with the goal of curing, which are more often than not inappropriate for someone with advanced dementia. Specifically for persons with dementia, these treatments include: 1) artificial nutrition through gastric tube feeding; 2) antibiotic therapy; 3) cardio-pulmonary resuscitation (CPR); and 4) hospitalization for infection. These are highly individual decisions that must be made based on the person's values and best interests. People with dementia and their families need information and

understanding about how to weigh the risks and benefits. Palliative care decision points are reached when the person with dementia is beyond understanding, and it is essential that family be involved, and provided with appropriate education and support.

The two case studies that follow illustrate key elements of the Beatitudes model in practice. Guiding principles are interwoven through these cases.

Case Study #1

Sharon C's husband, Anthony, was diagnosed with Alzheimer's disease in 2005. As the disease progressed, Sharon struggled with taking care of her husband at home. During the difficult period when Anthony wandered, he ended up in ERs, private psychiatric facilities, and homes without Alzheimer's units. Some facilities rejected him. Finally, a little over two years ago, Sharon was able to place him in a facility with a floor specifically for people with dementia, at Isabella Geriatric Center, just at the moment when Isabella became a partner in the Chapter's palliative care project.

When Anthony first arrived, staff had difficulties getting him to bed at night, and difficulties getting him up in the morning in time for breakfast. He was very resistive, emphatically pushing staff away. When they explored this with Sharon, they learned that it had been Anthony's habit for many, many years to stay up late (often as late as 4:00 a.m.), then snack before going to bed, often sleeping until noon or later the next day. With Sharon's encouragement, they experimented

with adjusting Anthony's care plan, and now, as Sharon says, *"the staff tells me that Anthony is the poster boy for letting patients sleep late. It is a great example of how to treat a person with dementia and tailor to his needs. So now, they let him sleep in if he doesn't want to get up. They let him have his own routine. They know and provide the food he likes (fruit and salads especially during the day, and sandwiches, yogurt and/or cookies at night). He has good days and bad days, but staff know how to connect with him, and how to work with him."*

She goes on to say, *"Like most people, I didn't get the meaning of palliative care. Most people think it is for people with six months to live. The real meaning of palliative care is relieving and preventing suffering. If anyone thinks an Alzheimer's patient doesn't suffer... they do, in the brain. I am so relieved he is here. Even though it's an hour and a half travel each way for me, I don't care. He has blossomed with the caring people he has now. He has a better life there than he had at home with me. Once they found a way to make him comfortable, and he was no longer on so many drugs, his personality came back, his sense of humor, his pleasure in dancing. I got my husband back! Anthony has a roommate, and he takes care of him. Anthony takes him for a walk down the hall. My heart just bursts with joy when that happens. It brings tears to my eyes."*

This story illustrates the organizational elements that need to be in place in order to support staff to provide appropriate care for Anthony: 1) facility policies and proce-

dures that support flexibility in waking and sleeping; 2) a care plan that both addresses Anthony's particular needs with regard to this flexibility and ensures that all staff, including weekend shifts, holiday replacements, etc., know and understand these needs; 3) food that Anthony likes is available in the middle of the night; 4) food that Anthony likes is available when he awakens in the early- to mid-afternoon; 5) all three daily shifts need to support each other in this adjustment in schedule (rather than asking, for example, why the night shift didn't get him up before they left); 6) interaction with families occurs as soon as someone is admitted to learn about the resident's routines and specific comforts and discomforts; and 7) ongoing conversation with families about what is working and what isn't, as evidenced by the resident's level of comfort, especially as the resident's needs change over time.

Case Study #2

The staff identified a resident, N.D., who usually sat with her peers in the dayroom and tended to yell out repeatedly throughout the day, seemingly without a break. To see if they could determine why she was in distress, the staff used three tools introduced by Beatitudes. Two of these were 'Spotlighting' and 'Road Mapping.' To 'spotlight' means that the team talks each week about the particular behavior the resident displays ("What is the resident trying to tell us?"), and then completes the 'Road Mapping' tool which acts as a guide or map to lead the staff in the direction of finding a solution. These tools help staff identify specifically when the

behavior occurs, what is taking place when the behavior occurs (including possible precipitating factors), and then guide staff in looking for ways to make the resident more comfortable. They help staff consider possible alterations of elements related to the resident's care or environment, and encourage them to try something new in their approach to the resident or in their delivery of care. Sometimes the environment needs to change, while sometimes it's the way care is provided that needs to change. Sometimes, however, behaviors such as yelling, hitting, cursing, or resisting care may be caused by untreated pain the resident is experiencing.

Staff members learned to avoid words such as 'agitated' and 'combative' which tend to label or define a person with dementia, since labeling tends to prevent staff from looking for a reason for the behavior. The Roadmap asks the staff to consider all possible meanings of a resident's actions, what is happening in the environment, what activities are going on, what noises might contribute to resident's behavioral expressions, and lastly, all possible changes in the care plan that might help. In addition, each week the team revisits any changes being tried out in a resident's care, such as letting a resident sleep, singing a song or reducing noise around the resident to reduce the behavior. We utilized these tools at our weekly team meeting to help us with N.D. in order to try to discover the cause of her yelling and discomfort.

Staff started by brain-storming possible reasons for her yelling out. One team member suggested that the Day Room may be over-stimu-

lating for her, with all of the activities being just too much for her to tolerate. The Beatitudes approach teaches that over-stimulating environments can cause someone with dementia distress, so we reasoned that a calmer environment might help to bring her comfort. We decided to change where she sat; thereafter, we sat her in the doorway to her room rather than in the Day Room so that she could still observe the "action" in the hall, but not be so exposed to the over-stimulating noise of the day room. We observed her each week and felt that there was some improvement; but after a while she began to yell again.

The team met and wrote down possible causes. N.D. had a companion privately hired by her family, and one team member suggested that the one-to-one companion might be too much stimulation for her to tolerate. We decided to speak to the family about this and to suggest they discontinue the private companion because her presence might be causing N.D. to be uncomfortable. They listened to our suggestion and the reasons for it and agreed with our plan. When the privately hired companion was no longer coming in to sit by N.D., we observed that N.D. did yell less than before and she did seem more comfortable.

After a period of time, however, her yelling resumed. We met again to write down other possible paths that might bring her the comfort she deserved. One staff member suggested that maybe even sitting in her doorway was too much stimulation for her as she was someone who really wished for and needed a

very quiet environment, especially as her dementia advanced. We tried sitting her in her room near the window where she could see the outdoors and the sky. At the same time, we also began playing her favorite music softly on her radio. We observed this had a calming effect on her. We continued to discuss her comfort level each week over the course of several months. However, her yelling was never fully eliminated, which concerned us.

We continued to brain-storm solutions, and reviewed what we were taught through this project, that people need a balance of stimulation (not too much and not too little), and determined that we still did not have the right balance to make N.D. completely comfortable. We continued to try to find the best balance for her, and decided on a rotation of sitting areas for N.D., periodically moving her from her doorway to inside her room so she can look out her window (and back again). Our Therapeutic Recreation Director suggested creating an opera iPod music program for her as a way to help soothe her. The combination of moving N.D. from an engaging activity to a calming activity really seemed to help N.D., and still does.

During this time, we also thought she might be experiencing untreated pain. To explore the possibility that some of N.D.'s behavior might be the result of untreated pain, all three shifts used a behavior-based pain assessment (the PAINAD). It was important to capture N.D.'s possible experience of pain over a 24-hour period. Based on the results of the assessment, pain medication was prescribed for N.D.,

and, after trials involving different medications and different doses at different times of the day, our team believed that much progress had been made in identifying and treating N.D.'s pain, and that we now had a good system of medication monitoring to meet her pain needs.

Finding the solution to bringing N.D. comfort took many steps and several months. We never gave up and tried various changes to help bring her comfort. We changed her sitting environment, asked the family to discontinue her private companion, which was counterintuitive, as most think a one-on-one companion would help to calm a person with advanced dementia, addressed her untreated pain, and introduced new music.

Sometimes finding the solution to a resident's distress can be fast, but at other times it can take a lot of time. We have learned that we must keep searching for the reason because there is always a reason for a resident's discomfort. N.D. is calmer now and her plan of care is to keep her in a quiet environment most of the day, recognizing, however, that she also needs the stimulation of some activities like music and visits from the staff. She still occasionally calls out, but we do not think that this is caused by pain because we assess her pain regularly. We continue our rotation of activities for N.D. and try to anticipate when she needs a change of pace, knowing all the time that she, like all of us, needs a balance of stimulation and peace and quiet.

Conclusion

Palliative care does not mean giv-

ing up. It does mean taking active steps to discover what comforts someone and what gives pleasure, as well as taking active steps to prevent or avoid unnecessary pain and suffering before they take hold. For people with dementia and their families, comfort is an essential point of focus every step of the way, not only at the end of life.

Study Questions

1. Why is it important to adapt policies and practices in palliative care to the needs of people with dementia?
2. Why might some aggressive medical procedures be inappropriate for people with advanced dementia?
3. Why is comfort an important concept in caring for people with dementia, and how might comfort principles be important in caring for frail elderly people who do not have dementia?

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Related Resources

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About the Author



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